

# **The Psychosocial and Physical Effects of Respite Care on Informal, Spousal Caregivers**

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**Ph.D**



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## **Abstract**

The impact of caring for a chronically ill relative or friend is well documented. Adverse effects have been reported on both physical and psychological well-being. Respite care is a principle form of intervention aimed at alleviating the impact and burden of the caregiving role. However, little is known about the exact nature and stability of its effects on carers' well-being.

This study utilised a sample of 112 spousal carers to examine the short-term effects of a single episode of residential respite care on carers' self-reported well-being, salivary cortisol and care recipients' level of dependency. Concurrent comparisons were made between groups of carers receiving and not in receipt of respite.

Respite care had a significant and positive effect on carers' self reported well-being, but the stability of these effects after the respite period had ended depended on the outcome employed. It was also found that respite had a more positive impact upon carers when they were able to increase their social activity during the respite period, although the findings also suggested that respite provision itself did not necessarily affect social activity to any significant degree. The effects of respite on salivary cortisol levels directly contrasted at times with the effects on self-reported well-being.

Changes in care recipients' level of dependency were found to impact immediately and significantly upon carers' well-being, regardless of whether or not respite care had been provided. Finally, the study included the development of a respite evaluation scale that had a clear factor structure, good internal reliability and some predictive validity. This scale may prove useful in future studies of respite care.

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Other colleagues and friends contributed greatly to the completion of this thesis. Most notably, Jan Stygall provided ongoing support and inspiration, especially at some very difficult times. Thanks also go to the author's partner and family whose love sustains her in both her life and work. This thesis is dedicated to the author's father, Thomas McNally, who passed away in 2004, but whose memory continues to be a great source of strength.

Final thanks go to those who participated in this research. The time spent talking with both carers and those in receipt of their care taught the author more than she could ever have written in the pages of this thesis.



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# **Chapter 1: Introduction**

## **1. Caring in society**

### **1.1 Prevalence of informal caring in the UK**

### **1.2 Methodological Issues in Prevalence Estimates**

## **2. The experience of caring**

### **2.1 Demographics**

### **2.4 Kinship relationship**

### **2.5 Care recipient condition**

## **3. Respite Care**

### **3.1 The nature and meaning of respite**

### **3.2 Respite Care in the UK**

## **4. Overview of thesis**

## **1. CARING IN SOCIETY**

### **1.1 Prevalence of informal caring in the UK**

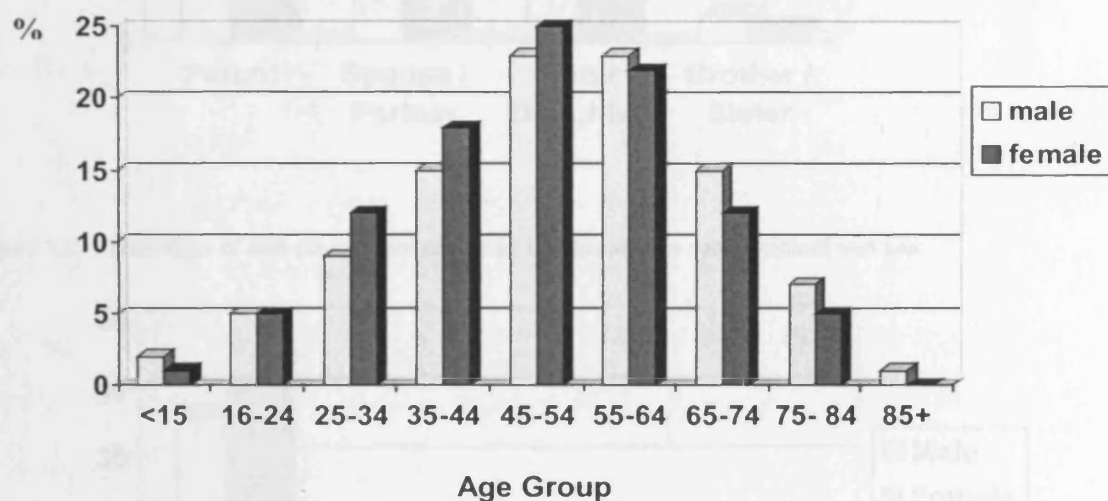
The UK population is getting older. According to the most recent UK census in 2001 (HMSO, 2001), while the proportion of the population aged under 16 has decreased by 4% since 1951, the proportion of the population aged 60 and over has increased by 5% in the same time. Those over 60 now make up a total of 21% of the whole population, and thus, for the first time ever, there are more people aged over 60 than there are children.

The ageing of the UK population is particularly evident when we consider the oldest age groups in our society. While in 1951 people over 85 represented just 0.4 % of the total population, this age group had by grown by the 2001 census to make up 1.9 %, totalling just over 1.1 million people (HMSO, 2001).

The ageing of the population reflects longer life expectancy due to general and widespread improvements in our standard of living, as well as improvements in health care practices. However, as life expectancy increases, so do the number of people with chronic illnesses requiring care (Llewelyn & Payne, 1995). For example, it was recently estimated that the number of people worldwide with dementia will double every 20 years to 81.1 million by 2040. While the highest increases will be seen in developing countries, the estimations for western Europe are still startling, with predictions of a 102% increase in the number of dementia cases between 2001 and 2040 (taking the total to around 9.9 million cases) (Ferri et al, 2005).

Changes in attitudes to care in the community, as well as recent trends towards reducing health care expenditure, have led to the full-time care of chronically ill individuals becoming the responsibility of families and friends. In the UK, recent estimates of the number of informal carers in the UK have reached around six million, with one in eight adults reporting that they have an informal caring role (Carers UK, 2006). The Family Resources Survey (Dept of Work & Pensions, 2006) has estimated that almost a half of all carers are aged between 45 and 65, and are therefore of working age (see figure 1.1). Approximately a quarter of the carers in our population are over 65, while 1 to 2 % of carers are children aged between 5 and 15.

Figure 1.1: Percentage of all Informal Carers By Age & Sex (Family Resources Survey 2005 – 2006)



It is also notable that throughout most of the working-age groups, a greater percentage of the carers surveyed are female. However, a higher percentage of the men surveyed are found to be caring at the later stages in life. Gender differences in caring are discussed in more detail later in this chapter (section 2.1).

In considering the nature of informal caring in society it may also be useful to consider who is in receipt of the care. This, along with several other factors, will determine the experience and consequences of a caring role. Figures 1.2 and 1.3 illustrate the findings of the Family Resources Survey regarding care recipients both within and outside of households respectively.

Figure 1.2: Percentage of *co-resident* carers by relationship to care recipient and sex

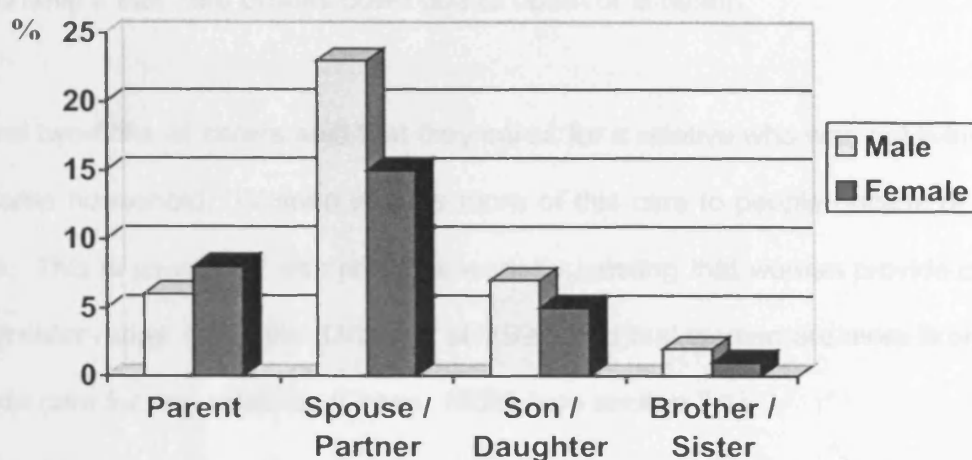
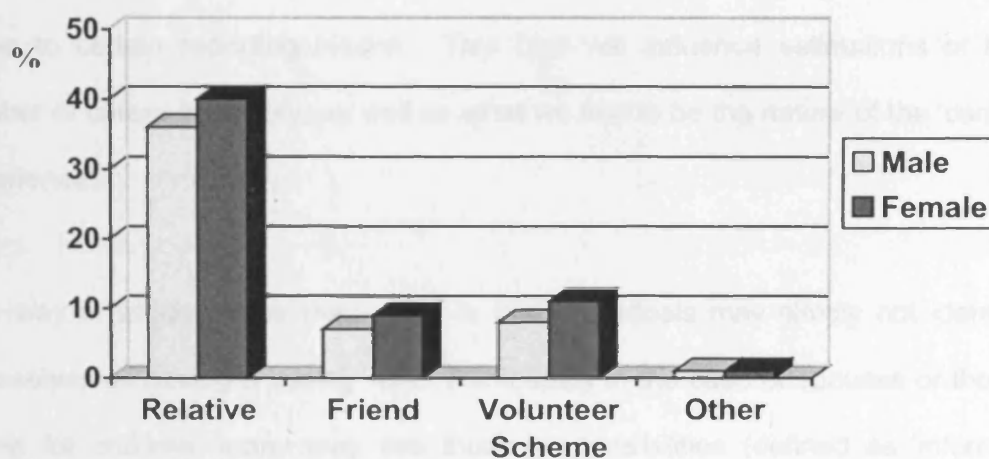


Figure 1.3: Percentage of *non co-resident* carers by relationship to care recipient and sex



\* from data published in Family Resources Survey, (HMSO 2002)

By far the most common recipients of informal care are family members. Despite the lessening importance of extended family systems and the growth of the 'nuclear family' in recent decades, responsibility for the well-being of the sick still seems to be largely self-contained within the family unit. This is true for both co-resident and non-co-resident caring relationships. Spouses or partners are unsurprisingly the single most common recipients of care. The primary care of a chronically ill person is only likely to be taken outside of the spouse / partner relationship if that care breaks down due to death or ill-health.

Around two-fifths of carers said that they cared for a relative who was not living in the same household. Women provide more of this care to people outside of the home. This is consistent with previous work suggesting that women provide care to a greater range of people (Orbell et al. 1992) and that women are more likely to provide care for non-relatives (Green, 1988) (see section 2.1).

## **1.2 Methodological Issues in Prevalence Estimates**

It should be noted that any investigation of involvement in informal care might be prone to certain reporting biases. This bias will influence estimations of the number of carers in society, as well as what we find to be the nature of the 'caring experience'.

One way in which a bias may occur is that individuals may simply not identify themselves as having a 'caring' role. Particularly in the case of spouses or those caring for children, many may see those responsibilities (defined as 'informal caring' by researchers) as just a natural part of their role in a family. They may not see their helping behaviour as in need of further definition beyond their kinship role.



Evidence for variance in the tendency to identify oneself as a 'carer' comes from several studies. For example, findings suggest spousal carers may be less likely than others to identify themselves as 'carers' (Orbell & Hopkins, 1993; Ungerson, 1993). Sex differences may also exist, with women being less likely to label their help for another as representing a 'caring' role (Parker, 1992).

As a result of caring activity not being identified as such, estimates of the extent of informal care in society may only be the 'tip of the iceberg'. What is more, any growth in the number of 'carers' in society is likely to be, in part, the product of a greater awareness of the term 'carer' and a result of more people identifying themselves as such to external agencies.

While large scale surveys may be said to 'under-estimate' the prevalence of informal caring in the UK, it may also be true that in another way they 'overstate' the impact of caring. This may be, in part, a function of how questions are phrased in surveys.

The number of people estimated to be caring in any survey depends on how that survey defines 'caring'. Many of the large-scale, national surveys have employed very general questions asking for reports of *any* caring responsibilities (eg- the General Household Survey (Green, 1988). Such studies have revealed figures of several million 'carers' in the UK. However, if we define more stringently what we mean by 'carer' the figures can change drastically. For example, the General Household Survey estimates 6 million carers to be providing some care to a relative or friend. However, if we then examine how many of that 6 million were actually bearing the main responsibility for the care of someone, the figure drops to 3.7 million. If we go further, and only include those spending at least 20 hours

a week in informal caring work then the number of carers falls to 1.7 million (Twigg, 1992).

It is likely that the population of 'carers' as defined in large scale, national surveys are not the same population as that drawn on in the majority of carer research. Many studies examining morbidity among carers, for example, draw samples from carer support groups and carer organisations (Schulz et al. 1990). It could be argued that individuals are unlikely to join these support organisations unless caring has a significant impact upon their lives. What is more, while an individual with 'light' caring responsibilities may well respond to a general, census style, survey covering a range of issues, they may be less likely to feel it appropriate to participate in an involved study devoted to caring and its consequences. Thus, when considering the extent of caring in society we may need to consider that the findings of many research studies do not apply to all of the several million 'carers' identified by large scale surveys. Rather they apply to subset of that population more deeply involved in a caring role.

## **2. The experience of caring**

Before considering the consequences of carer burden for health and well-being, it is important to explore the nature of that burden, that is, the experience of caring. One reason why this is an important step in a consideration of caring in society is that there is no single and easily definable set of experiences that characterise caring. While there is likely to be a degree of overlap in the caring experience, that is, certain issues or stressors that face all carers, caring roles are likely to be as heterogeneous as the population of carers itself.

Carers can be defined along a number of dimensions relating to who they are and who they care for. An appreciation of how the caring experience can vary according to these dimensions may be considered fundamental to the validity of research in this area. Without it, carers may be inappropriately considered together as a homogeneous group that may result in invalid research questions, insensitive measurement and inconsistent (or even contradictory) findings.

## **2.1 Demographics**

Each of us occupies a place within a network of several socio-demographic dimensions that we use to define both others and ourselves. For example, we may be defined according to our sex, our age, our ethnic background and our social class. The experience of a caring role, as with the experience of life in general, will to some degree depend upon one's socio-demographic status in society.

Research findings have already been introduced that would suggest men experience caring differently from women (eg – Orbell, 1996). In relation to the consequences of caring, review level evidence suggests that the prevalence rate of depressive disorders is higher for female carers than it is for their male counterparts (Cuijpers, 2005).

A higher rate of depression among women is not phenomena restricted to informal carer samples, and indeed, is a robust finding across many areas of work (Hankin & Abramson, 2001). However, there may be reasons specific to the caring role that makes female carers more vulnerable.

Taken as a whole, research evidence seems to suggest that caring is a more 'all-encompassing' experience for women. For example, research suggests that women may provide more intensive and complex care; experience more difficulties in balancing caregiving with other family and employment responsibilities; suffer from poorer emotional health secondary to caregiving; and cope with caregiving responsibilities by forgoing respite participation (Navaie-Waliser et al 2002).

The more all-encompassing caring experience of women may result in part from the assumptions that we hold as a society regarding appropriate sex role behaviour. For example, Brody (1981) found that people of all generations expected daughters rather than sons to give up work in order to take on the care of a parent.

The influence of socio-demographics upon the caring experience goes beyond our sex, however. More specific aspects of our cultural identity, such as ethnic background and socio-economic status are also likely to be important. In particular, both of these factors may influence the resources that are available to carers to help them cope with their role.

Regarding ethnic background, the resources and services available to carers are often organised around a 'white norm', which may ignore or contradict the value systems inherent in many of the cultural groups that exist in our society (Twigg, 1992). One example may be that day centres may not provide food appropriate to many carers' cultural beliefs. What is more, language barriers, particularly in first generation members of ethnic minorities, may prevent adequate awareness of

services. Netto (1998) observed that the low uptake of services by non-white carers might be accounted for by a general lack of awareness of the availability of these services as well as clear preferences for service delivery, which are currently not being met.

Aside from one's cultural background, another influence on the caring experience and the resources available may be one's social class. While large-scale surveys (eg- Green, 1988) have not found informal caring to be the province of any one social class, there are important differences according to social stratification.

Maybe most importantly, working class carers are far more likely than their middle class counterparts to provide co-resident care and therefore experience a more all-encompassing caring role (Arber & Ginn, 1992). The caring role may also be all-encompassing for working class carers since, like women, they are more likely to give up work to provide care (Parker, 1992). Unlike in the case of women however, this decision may be forced more by pragmatic concerns than by societal norms. Working class carers are more likely to have manual occupations or other forms of employment that have little flexibility in relation to working from home (Twigg, 1992). Thus, an involved caring role is less likely to be compatible with one's career and the latter more likely to be sacrificed.

One final socio-demographic factor that may influence the caring experience is age. As was evident in the surveys cited above, there are carers within our society at all age groups, from children to the very elderly. One's age may influence the experience of caring in a variety of ways. First, across the population, age is associated with poorer social conditions and lower socio-economic status, thus bringing to the older carer all the consequences of low

social class discussed above. Beyond this, however, age also can bring physical limitations, which can be especially problematic if the cared for person requires substantial physical care (eg – lifting in and out of the bath or bed) (Twigg, 1992). This, combined with a lower level of financial resources with which to purchase labour saving apparatus (hoists, stair lifts etc) may add significant physical strain to the caring experience of older carers.

The effects of age may go beyond the physical experience of caring however. Age can also bring with it a greater degree of social isolation. This is in part a natural consequence of the aging of one's family and friends, with many dying or becoming housebound. However, the isolation of older carers may also be exacerbated by the attitudes of others. Twigg & Atkin (1993) report that, while developing a social life for younger carers is generally seen as an appropriate use of service resources, less concern was observed with breaking the isolation of older carers. It may be that we, as a society, see older people as less in need of a social life. As will be discussed later, however, social support and particularly social interaction may be vital to the health and well being of carers of all ages.

## **2.2 Kinship relationship**

While the experience of caring will be influenced a great deal by our position in society, it will also be determined by the position of the person we are caring for in our own social network. As discussed earlier, the vast majority of carers look after someone from within their own close family. However, even within the group of family carers there is variation that may have enormous consequences for how one experiences a caring role.

The most common receiver of informal care is a spouse or partner (HMSO, 2001). Indeed, it may be that one reason for the rapid growth in the total number of carers is an increased tendency for carers of a spouse or partner to be identified as such rather than their care being seen as merely an extension of marital responsibility.

With this in mind it may be that the over riding aspect of the experience of caring for a spouse may be that it is 'expected'. The marriage vows themselves pertain to promises pertaining to a relationship existing 'in sickness and in health' and it is less likely that a spousal carer will be seen as doing anything more than his/her 'duty'. One consequence of this view is that support from outside sources may be less forthcoming to spousal carers (Green, 1988). Just as in the case of the elderly, they may be seen as in less need of a social life outside of their own home and marriage.

Twigg & Atkin (1993) reported that many spousal carers, aside from receiving less social support from outside sources, may also be reluctant to engage in any social activity if it can't include the one they love. Indeed, guilt has been shown to play a major part in the experience of spousal carers (Gruffydd & Randle, 2006). Guilt may have an adverse effect on the willingness of carers to access services that may facilitate opportunities for social interaction (such as respite services or substitute care) as well as the benefit derived from social interaction when it is accessed.

This lower level of support may be an ironic facet of caring for one's spouse or partner since one's major source of support (the spouse) has in many cases been partially or totally eradicated. The transformation that takes place in a spouse or

partner with a dementing illness for example can lead to the carer being unable to relate to that person in the way they used to. In line with this, many studies (eg- Sanders & Adams, 2005) have observed a sense of loss among carers, often resembling a bereavement process.

If a spouse or partner is unavailable or unable to provide care then responsibility will often fall to the children. This form of caring, often referred to as 'filial', is far more likely to involve the adoption of a primary caring role by a daughter than a son (Orbell, 1996), and thus, just as in the case of spousal carers, there may be an element of duty and societal expectation involved in this form of care.

One immediate implication of taking on the care of one's parent is the effect that the new role has on existing caring responsibilities (eg – to one's own children). Role conflict may ensue, resulting in added stressors for the carer beyond those directly connected to the caring role (eg – conflict with spouse / partner or children). For example, stress in the roles of mother and wife has been found to exacerbate the effects of caring for a parent and worsen psychological well-being (Stephens & Townsend, 1997).

One other particular source of stress facing those who care for parents concerns physical intimacy. The performance of physically intimate tasks may be seen as less acceptable (and more stressful) when performed by a son or daughter for a parent than in the context of a parent caring for a child or even spousal caring (Lewis & Meredith, 1988). This can lead to anxiety and a loss of dignity on the part of both carer and cared for person.



### **2.3 Care recipient condition**

The experience of caring will, of course, be influenced by who one is caring for, and included in this, the medical condition they are living with. Illness characteristics will determine what needs to be done, and how often, as well as potentially affect the response of the care recipient to the carer. While informal care is provided to individuals with a wide range of illness, two major dimensions of impairment can be identified and examined, that is, physical and mental.

A physical impairment can often create a physical strain for the carer. Who may themselves be suffering from physical problems such as back trouble, painful joints, or simply a lack of strength due their young or advancing age. The fact that carers often receive none or little instruction in manual handling can amplify the physical costs of a caring role.

Maybe even more distressing to carers, however, is the mental aspects of a care recipient's condition. To see a person that one has known and loved for many years become changed in relation to their personality, possibly even to the point that they are no longer able to recognise those close to them, is inevitably distressing.

Mental impairment, of course, also brings with it stigma. Full time carers, who may already be prone to social isolation due to the constant demands of their role, may often close the door on their network of friends and family for fear of the care recipient's behavioural problems causing embarrassment or offence. In this way, stigma leads to social isolation (Tsang et al., 2003).

The nature, conceptualisation and measurement of a care recipient's condition, as well as its potential impact and costs for the carer, are discussed in more detail in later chapters.

### **3. RESPITE CARE**

#### **3.1 The nature and meaning of respite**

The term respite is widely used and at its simplest refers to providing somebody with a 'break' from an onerous task. Respite care, as provided to informal carers and care recipients, can take many forms but its meaning can vary depending upon who is defining it.

Respite care involves the individual with a disabling condition being supported, either in a hospital/nursing home environment or at home, for a limited period of time. Some definitions of respite care imply that it is aimed at providing the care recipient 'with a break from their primary carer (Social Services Inspectorate, 1993). However, it is more generally accepted that it is the carer who is intended as the direct beneficiary, with the aim being to exert a positive effect on their well-being during and after intervention, thus enabling them to continue in their caring role. For example, the UK National Strategy for Carers (1999) places emphasis on support for the carer directly, and has funding for respite breaks at its core (see next chapter for more on this).

The assumption has generally been that relief from the burden of care serves much like a holiday from work and enables the individual to re-energise themselves for the tasks ahead. Aside from such immediate benefits, respite care

may also facilitate activity that enhances well-being after the respite period has ended. This may include making improvements or repairs to the home, or perhaps attending to business with a bank manager or solicitor. In addition, respite care may enable the carer to resurrect or maintain social relationships that they may not have had the time to devote to while caring.

There are several types of respite breaks for carers. They include:

- A short stay for the person being cared for in a residential care home
- Care services in a day centre
- In home respite services, either in the day or over night

The meanings attributed to respite by those who use the service are more complex, however. In a qualitative study of 294 carers in Canada it was found that carer's understanding and use of the term 'respite' differed to that set out by policy makers (Chappell et al. 2001).

When asked what having a break meant to them, two main themes emerged. These were '*Internal respite*' and '*External respite*'. The former encompassed the idea of 'stolen moments' or brief periods of time away from the activities of caring. It also referred to periods where the care recipient is relatively happy or comfortable thus providing a break from the condition rather than the person being cared for. Some carers minimised the importance of having a break, claiming that they did not carry out enough caring tasks to warrant needing a break.

External respite on the other hand referred to what is understood from a policy-maker's perspective of having a break. For example, this may be the sense that a

break means absolute physical and mental relief from caring, or an opportunity to see friends and relatives outside of the caring role.

It was found that over half of the carers interviewed tended to talk about internal respite rather than external respite. Chappell et al (2001) suggest that, since many carers define what respite means in terms that do not actually remove them from the caring role, this demonstrates that respite care as defined by policy-makers may only benefit those carers who define it in 'external' terms.

Evidence of a gap between the 'meanings' of respite emanating from a policy makers perspective and those held by service users suggests the value of a 'person-centred' approach to both service provision and evaluation. That is to say, rather than make assumptions about the value of intervention to carers, a more fruitful approach may be to conduct evaluations of benefit from the carers' perspective.

### **3.2 Respite Care in the UK**

Respite care has steadily moved to a central position in the framework of support to informal carers. In the UK, the Carers Recognition and Services Act, implemented in 1995, meant that caregivers became entitled (at the time the person they care for is assessed for community care services) to an assessment of their own needs and situation, the results of which should be taken into account when decisions are made about the services provided to the care recipient. However, this act did not give local authorities the power to offer carers' services to support them in their caring role, and it wasn't until the introduction of the Carers And Disabled Children Act (July 2000) that local authorities were given the

power to supply certain services direct to carers following assessment. In particular, the new act provides for local authority social services departments to run voucher schemes for short-term breaks or 'respite' care.

Of all the forms of intervention aimed at carers in the UK, respite care continues to be the most widely advocated. From a service user perspective, respite has been identified as the most commonly expressed unmet carer need (Kersten et al., 2001). From a nationally policy perspective, the National Strategy for Carers makes explicit that:

" Supporting the independence of carers means allowing them to have some time on their own, or for themselves. This means time to pursue their own interests, to see their own friends, take care of their own needs or just catch up with jobs around the house. A break from caring is invaluable in reducing the psychological and emotional stress faced by many carers. Access to support services and breaks can also help carers to continue providing the support they give to a sick, disabled or elderly person."

This statement would seem to suggest that respite care is high on the 'carer support' agenda, as would the funding invested in its provision. The Carers Special Grant, that was made available to local authorities and aimed at allowing carers to take a break from caring, totalled £140 million for England over three years (£20 million in 1999/2000; £50 million in 2000/2001; £70 million in 2001/2002), and has since been renewed on a regular basis. The current extension is up to 2006, and the level of funding has been increased to £185 million (Arksey, 2004).

A first glance, these figures may seem impressive. However, while the funding undeniably does represent a significant improvement on previous funding levels,

the money invested into respite care does need to be seen within the context of how much carers actually save society.

Carers UK (2002), based upon figures from national studies such as the General Household Survey estimated that, at an hourly rate of £9.95, the support provided by informal carers could be valued at £57.37 billion per year. Furthermore, since these calculations were based on population data that is now several years old, the actual figure is now likely to be much larger.

Another point to bear in mind when considering the level of funding invested into respite care is the gap between official levels of service provision (in terms of what is being made available) and the extent to which those services are reaching the intended recipients. In particular, research on the extent to which respite care is utilised by carers may be seen to suggest that there are problems in its provision. Relatively few carers appear to make use of short-term admissions (Chappell et al., 2001), and data from the National Strategy for Carers suggests that usage of respite is patchy. The most commonly used form of respite is that provided by support from friends or family (2.3%). Only 1.3% of all carers used a residential respite facility where the person being cared for was looked after in a residential home, nursing home or similar facility.

There may, of course be other influences on the uptake of respite besides its perceived benefits. For example, cultural issues may be important, highlighted by the fact that both carers and care-recipients from ethnic minorities have been found to be less willing to utilise respite services (Kosloski et al, 2002).

Despite this, however, it seems clear that given the investment made each year in respite care provision, and its central role in systems of carer support, that the question of the effectiveness of respite in achieving its aims is examined.

#### **4. Overview of thesis**

In chapter 2, the aims of respite care are examined more fully. In particular, the targets of respite provision in terms of *who* it is aimed at, and *what* it is aimed at, are discussed. In chapters 3 and 4, the concepts related to the aims of respite care are examined in detail. Chapter 3 examines the global endpoints of psychological and physical well-being among carers, and then goes on to look at the more population specific concept of 'carer burden', including an extensive examination of the conceptualisation and measurement of care-recipient impairment. Chapter 4 then goes beyond the more traditional outcomes of intervention and examines the concept of social functioning. All the concepts discussed in the previous chapters are brought forward into chapter 5, which provides a systematic review of the literature examining the effects of respite care.

In chapters 6 to 10, a prospective study of the effects of a single episode of residential respite is described. Chapter 6 outlines the aims and hypotheses of the study while chapter 7 relates back to the evidence provided in earlier chapters in a detailed description and justification of the methods used. Findings relating to a baseline analysis of the data are described in chapter 8, followed by report on the prospective analyses of the effects of respite in chapters 9, 10 and 11. Finally, the findings are discussed and conclusions made in chapter 12.

## **Chapter 2: Targeting the effects of respite care**

- 1. Who should be target of respite care?**
  - 1.1 Community care reforms**
  - 1.2 Recognising carers**
  - 1.3 A 'dual focus' on need**
  - 1.4 The implications of a 'dual focus' on service evaluation**
  
- 2. What should be target of respite?**
  - 2.1 A 'Biopsychosocial' approach to outcome evaluation**
  - 2.2 The concept of 'effectiveness' in respite care**
  - 2.3 Outcome assessment: Generic or Population Specific?**



## **1. Who should be target of respite care?**

### **1.1 Community care reforms**

Community care existed long before community care policy. Helping relatives and friends who need care to live within the community has been a fundamental challenge undertaken by a sizeable proportion of the population across many generations. Yet, up until relatively recently, this challenge, and its impact, was rarely recognised. It is the aim of this section to trace the development of UK policy on informal care and examine its implications for both respite care and its evaluation.

Before the community care reforms of the early 1990s, informal care for a relative was usually seen as simply an extension of the carer's role as a wife, husband, parent or child. After the reforms, however, carers began to be seen as an identifiable group in society, with equally identifiable challenges and needs. In many ways, they moved far more towards the centre stage of social and health care policy (Baldwin and Parker, 1989).

According to Powell (1990), the N.H.S and Community Care Act (1990) may have its origins in the central planks of UK government policy throughout the 1980's to promote internal commissioning and provider roles to stimulate the 'buying' and 'selling' of in-house services. Many services had to be subjected to competitive tendering and, as a relatively large expense; community care for older people became an obvious area for the application of this approach. This was particularly true in the context of what Powell calls the 'demographic apocalyptic projections' being made about older people and their likely need for support. This policy essentially channelled public sector funds into the private institutional sector

while leaving the domiciliary sector chronically under-resourced. Criticism of this led to the Griffiths Report (1988), which proposed that local authorities were strategically well placed to oversee the delivery of community care within the matrix of policy and professional practice.

## **1.2 Recognising carers**

Along with the growth of care in the community came the recognition that this care has an impact on those providing it. In 1979, Fengler & Goodrich first coined the well now known phrase 'hidden patients' in reference to caregivers and the potential of their caring role to be a cause of poor health and well-being. Since then, a substantial amount of research has been conducted with aim of identifying the consequences of caregiving for health and well-being, as well as the most effective forms of supporting carers and attenuating these consequences.

In practice, however, the 'end point' of increased services and support in the community was the cared for person (Parker, 1999). That is, the main purpose of any intervention was to support carers to continue caring, and avoid the need to replace them.

One consequence of the community care reforms was the introduction of case management. One intended consequence of this was to improve the targeting of community care so that services were more focused on the most disabled people in the community as well as to improve the effectiveness of community care services. Carers were often left out of the 'case' that was 'managed' however. Studies revealed that, in the first few years after the N.H.S and Community Care Act was implemented, only a small proportion of carers had received an

assessment of their own needs and that they were less satisfied with their own assessment than that of the person they supported (Warner, 1995). It was also evident that care managers tended to under-estimate carers' needs (Watson & Taylor , 1996).

It wasn't really until the introduction of the Carers (Recognition and Services) Act (1995) that carers' needs were formally taken into account. The act gave carers a right to an assessment of their ability to provide care if they cared for someone having an assessment under the NHS and Community Care Act (as well as under the Chronically Sick and Disabled Persons Act (1970) or the Children Act (1989). The Carers Act required the Local Authority to have regard to the result of the Carers Assessments when making decisions about services to be provided to the user. However, this did not extend to requiring the local authority to provide services for carers or providing any new funding for these services.

In 1999, the National Strategy for Carers allowed funds to be channels for directly to carer support with the introduction of a *Carers Special Grant*. The grant ring-fenced funding available to local authorities for the enhancement of services to carers, including those allowing carers to take a break from caring. Later in the same year as the national strategy was announced, the Royal Commission on Long Term Care published it's report, which contained a note of dissent from two members of the commission which itself made recommendations.

**Table 2.1: Key Legislation and Policy Affecting Carers (since 1990)**

Legislation or Policy	Key implications
N.H.S and Community Care Act (1990)	<ul style="list-style-type: none"> <li>- Placed a duty on local authorities to carry out a needs assessment for anyone who might require community care services.</li> <li>- Placed a duty on local authorities to notify health and housing authorities and invite them to take part in the assessment where it appears there may be a need for the provision of their services.</li> </ul>
Carers (Recognition and Services) Act (1995)	<ul style="list-style-type: none"> <li>- Allowed carers who are providing 'regular and substantial care' to request an assessment of their ability to care ("a carer's assessment").</li> <li>- Placed a duty on local authorities to take the carer's ability to care into account when looking at what support to provide to the cared for person.</li> </ul>
National Strategy for Carers (1999)	<ul style="list-style-type: none"> <li>- Highlighted the importance for health, social care, housing, education and employers to ensure carers' needs are recognised and addressed.</li> <li>- Introduced a 'Carers Grant' to provide services directly to carers with the emphasis on enabling carers to take a break from caring.</li> </ul>
Carers and Disabled Children Act (2000)	<ul style="list-style-type: none"> <li>- Gave carers the right to request an assessment of their needs, even when the cared for person refuses an assessment.</li> <li>- Also allowed local authorities to provide carers with services and to provide direct payments for care services.</li> </ul>
Carers (Equal Opportunities) Act (2004)	<ul style="list-style-type: none"> <li>- Builds on existing legislation to ensure that all carers know that they are entitled to an assessment of their needs.</li> <li>- It also focuses on helping carers lead a fuller life and places a duty on councils to consider a carers outside interests (work, study or leisure) when carrying out an assessment.</li> </ul>
National Service Framework for Long Term Conditions (2005)	<ul style="list-style-type: none"> <li>- Recommends an integrated assessment of carers' health, social care and support needs <i>irrespective</i> of whether the cared for person recognises or accepts their own need for statutory services.</li> </ul>

### **1.3 A 'dual focus' on need'**

In the light of the National Strategy for Carers, the issue of whom the focus of intervention was on (ie – carer or care recipient) again became salient. As Pickard (2001) points out, policy documents differed according to where they placed the emphasis of supportive intervention. The Royal Commission clearly emphasises the needs and support of the care recipient. The approach was very much 'carer blind' and contained only 2 of 24 recommendations specifically focused on carers. Rather the carer was seen as being supported indirectly through the provision of better services for the elderly or disabled person. The National Strategy for Carers however had much more of a 'dual focus' (Twigg, 1996) and gave far more attention directly to carer support. It involved a three pronged approach made up of 'information, support and care'. Notable within this policy document was an emphasis on providing short-term breaks from caring.

The 'Carers Special Grant' was designed to stimulate diversity and flexible provision to meet individual needs, and in this way provide supportive services to help carers maintain their health and relieve stress. The grant totalled £140 million for England over three years (£20 million in 1999/2000; £50 million in 2000/2001; £70 million in 2001/2002), and has since been renewed on a regular basis. The current extension is up to 2006, and the level of funding has been increased to £185 million (although the ring-fencing element was removed in April 2004).

A study by the King's Fund (2001), however, suggested that the Carers Grant did not lead to a significant increase in the range and quality of breaks provided in its first two years of operation. An analysis of the second year of the grant (2000-1) by the King's Fund concluded that the money was going some considerable way to the promotion and provision of flexible breaks for carers, but that

implementation on a local level varied. It found that relatively few carers had benefited compared with the level of need that had been estimated.

Progress continues to be made however. A major step forward was the announcement of the Carers and Disabled Children Act 2000. This enabled local authorities to develop voucher schemes from that provided carers and care recipients with short-term breaks. Vouchers can have either a time or monetary value to allow maximum flexibility, and can be considered a compromise between direct payments and direct services provided by or on behalf of the local authority (DH, 2003). Critics have highlighted the fact that voucher schemes are not fully developed in many social services departments, and pilot schemes are reported to be running into difficulties due to a lack of services against which vouchers can be redeemed (Revans, 2001, Arksey et al., 2004).

The shift seems to be continuing towards a dual focus that sees the carers' needs as a focus of intervention as much as the care recipient. For example, it is notable that the recent National Service Framework for Long Term Conditions (2005) clearly recommends an integrated assessment of carers' health, social care and other needs, as well as the support they need in their caring role, together with a designated contact person irrespective of whether care recipient recognises or accepts their own need for statutory services.

The extent to which the focus is truly 'dual' has however been criticised. In particular, many feel that the focus has shifted too far away from the needs and concerns of the care recipient. As Pickard (2004) points out, a particular challenge has emerged from a disability rights perspective, from which it has been argued that policy should not endorse dependence through an emphasis on

supporting carers but should underwrite the independence of the disabled and older people they care for. The emphasis on the needs of carers, from this perspective, shifts attention and resources from the fundamental issue, that is, the support of the person in need of care. In particular, the national strategy for carers has come under the spotlight, and Lloyd (2000) commented that

“there is little evidence in the strategy of the perspectives of people who are cared for and in this respect it can be seen as divisive. Indeed it runs the risk of putting the interests of carers above those of the people who are on the receiving end of care”.

It could be argued that short-term breaks and respite are interventions that lie at the sharp end of this debate. While a very valued source of support for carers, the very concept that one is such a burden that a loved one needs a 'break' from you may be disturbing for the care recipient. Respite could conceivably be perceived as reinforcing the idea that the care recipient *is* the 'burden' and that their removal from the proximity of the carer is the most logical solution. Indeed, it has been with this in mind that official communications from the Department of Health began using the term 'short term break' rather than respite. As stated in *A Real Break* (Weightman, 1999), the guidebook for good practice, published in association with the National Strategy for Carers “the very term 'respite' is now thought to be inappropriate by many people. Much preferred is 'short-term breaks' for this has no bias, and implies that there must be benefit to both the carer and user.” The extent to which this represents a real step forward rather than simply a semantic 'dodge' is, of course, very debatable and the term respite remains in common usage by carers and service providers alike.

#### **1.4 The implications for a 'dual focus' on service evaluation**

It is clear that one implication of a 'dual focus' on need for any evaluation of services is that it is important to examine the effectiveness of support and services not just for carers, but also the effects on the older person who is being cared for (Pickard, 2004). This is not just about addressing the balance between the rights of the carer and care recipient, but also acknowledging the fact that the caring relationship is a 'dyad' and one in which the well being of one partner in the dyad will inevitably effect the other. Relating this specifically to respite care, if service provision negatively effects the physical or emotional well-being of the care-recipient, then this is likely to impact what the carer is required to cope with on the return of the care recipient into their care. As Zarit & Leitsch (2001) point out,

“Failure to examine the possible ramifications of the program on both members of the dyad and, indeed, on the larger social context, can lead to unanticipated outcomes as well as impeding the realization of benefits.”

Another implication of the shifting 'balance' between the needs of the carer and care recipient, however, is that respite services often lack clearly defined objectives, making a 'dual focused' evaluation difficult. This lack of clarity may extend to service providers, service funders and policy makers, and it may not always be clear whether the service is intended to benefit carers and/or care recipients or indeed other stakeholders. This issue is complicated by the fact that many chronic illnesses have a cognitive component that can impair choices about preferred care and make valid assessments of outcome problematic to elicit. Evaluating what works best for who is not clear-cut (Arksey, 2004).



## **2. What should be target of respite?**

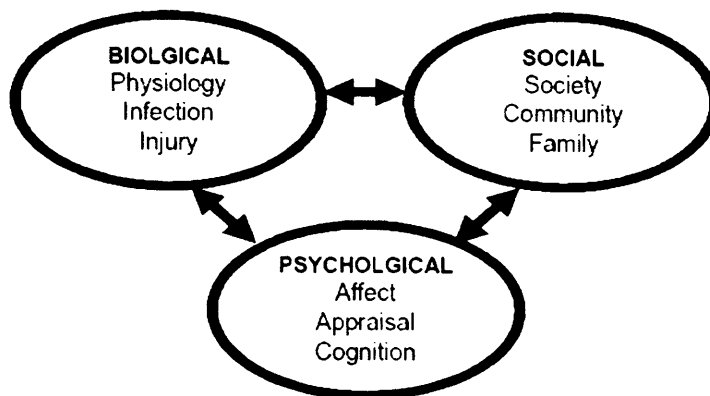
### **2.1 A 'Biopsychosocial' approach to outcome evaluation**

The last section reflected on who should be the focus in determining the effectiveness of respite. Discussed was the move towards a 'dual focus' that accounted for the needs of both carer and care recipient. However, even once the target of intervention is identified in terms of *who* should benefit, determining effectiveness also requires one to reflect on *what* a service is intended to protect or enhance. In other words, which specific dimensions of well-being are of interest, and how best can we conceptualise and assess these dimensions?

For many years, physical and psychological aspects of well-being were dichotomised in science. One of the many to break with this view was George Engel, an internist and practicing physician, who published a paper in the journal *Science* in 1977 with the ambitious title 'The Need for a New Medical Model: A Challenge for Biomedicine.'

Engel stressed the importance of a 'biopsychosocial' approach (see figure 2.2), and proposed that actions at the biological, psychological, and social level are dynamically interrelated and that these relationships affect both the process and outcomes of care.

**Figure 2.2: The interrelated 'biopsychosocial' system**



One way of understanding carers' well-being that is consistent with a 'biopsychosocial' approach is to focus on what is known about the processes of stress and adaptation. Oyebode (2003) highlights that *stress-process* models have been prominent in recent years in the frameworks for understanding the impact of informal caring.

For example, Pearlin et al (1990) have drawn up a framework that allows the demands and resources of the caregiver to be clearly identified. They define stressors as the "problematic conditions and difficult circumstances experienced by caregivers" that strain (or possibly overcome) the carer's capacity to adapt. There are two types of stressors identified: primary and secondary. Primary stressors are linked directly to the individual and the disability, while the secondary stressors arise from the demands of the caregiving role itself. Third variables, such as social supports, may moderate or mediate how people are impacted differently by the same stressors, and may help to sustain the caregiver and lessen the effect of the stressors. In relation to outcome, Pearlin et al.

suggest that stress among carers may manifest itself in their physical and mental health, as well as their ability to sustain their own social roles. The interrelationships among all these variables change and develop over time, and the Stress Process model suggests that

"Life events can lead to negative changes in people's roles, changes whose persistence wears away desired elements of self-concept, and that through this set of linkages stress is aroused. Coping and social supports, for their part, can intervene at different points along this process, thereby mediating the outcomes."

In total, Pearlin et al. distinguish four domains for evaluation: 1) background and contextual factors; 2) stressors; 3) mediators / moderators of stress; and 4) outcomes. A biopsychosocial view runs through each of these domains. For example, the outcomes specified in the model include the mental well being of the carer, the physical health of the carer, and of course, the impact on the ability of the carer to continue in their role. Also included in the model, among the mediators of stress is the effect caring has on the carer's social well-being (which may include one's career and one's social relationships).

## **2.2 The concept of 'effectiveness' in relation to respite care**

In relation to respite care, the National Strategy for Carers (DH, 1999) seems to reflect the biopsychosocial perspective. It makes clear that the immediate intention is that "a break from caring is invaluable in reducing the psychological and emotional stress faced by many carers" as well allowing carers "time to pursue their own interests, see their own friends, cinema or have a meal out."

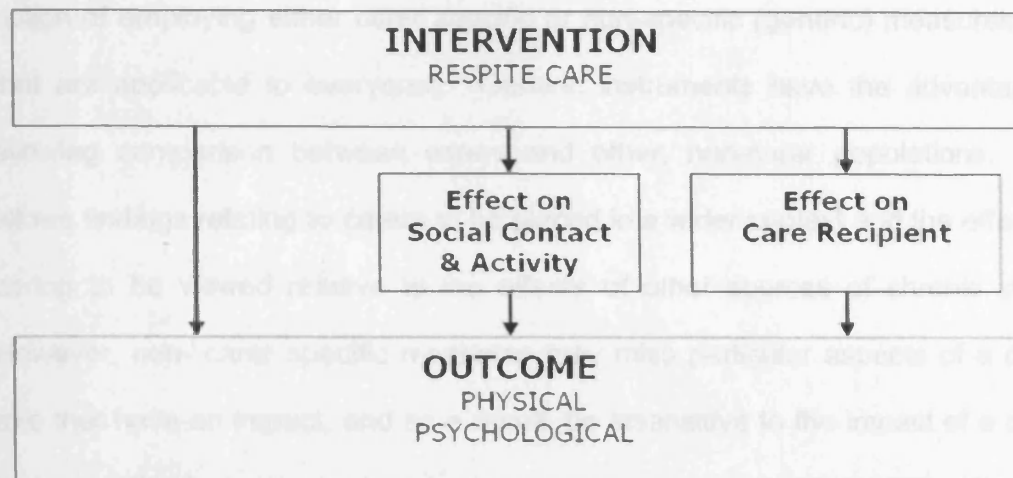
Importantly, this is all set out within the general proviso that, by offering support to carers, services must never result in the “taking away any of the rights of the people who need care, nor recognising their needs any the less.” Additionally, the functional benefits of respite are highlighted in that “Access to support services and breaks can also help carers to continue providing the support they give to a sick, disabled or elderly person.” It is this last aspiration that may be seen as the fundamental justification of investment in carer support and as much an aim relating to societal well being as to the well being of any individual.

From this ‘official line’, a (rather vague) list of some of the main aims of respite care may be summarized (see below).

- a) Reducing the impact of the caring role on carers’ well-being
- b) Allowing carers to maintain their ‘social’ life outside of the caring role
- c) To avoid any detrimental effects of carer support intervention on the cared for person
- d) To preserve the informal caring relationship over time.

It is possible to hypothesise how these aims may interact, from a carer’s perspective, to determine the experience and effects of respite (see figure 2.3). The experience of respite may potentially impact directly on carers’ psychological and physical well-being, as well as on the level of burden they perceive. Additionally, it is possible that the impact of respite on carers’ well-being and burden may be either moderated or mediated by the corresponding effects of respite on their social functioning and on their care-recipient’s condition.

Figure 2.3: Carers' experience of respite and its potential moderating / mediating factors



### 2.3 Outcome assessment: Generic or Population Specific?

If we return to the four aims of respite listed in section 2, the latter aim (preservation of the informal caring relationship) is relatively uncomplicated in its evaluation in that it is usually assessed simply in terms of the institutionalisation of the cared for person (although the validity as this as an outcome of intervention has been debated). The other three outcomes, however, are potentially more complex to work with.

All carers are people, but not all people are carers. That is to say, it is true that carers experience life along the same dimensions as the rest of the population (eg – in terms of psychological and physical well being) and so it makes sense to evaluate outcomes in carer research using the same indices as used in the rest of the population. However, it is also true that carers experience life in ways not within the 'normal' spectrum of experience, so it also makes sense to employ outcomes that tap into these extraordinary aspects of carers' lives.

Therefore, in considering outcomes in carer populations one is faced with the option of employing either carer specific or non-specific (generic) measures (ie – that are applicable to everyone). Generic instruments have the advantage of allowing comparison between carers and other, non-carer populations. This allows findings relating to carers to be placed in a wider context and the effects of caring to be viewed relative to the effects of other sources of chronic stress. However, non- carer specific measures may miss particular aspects of a caring role that have an impact, and as a result, be insensitive to the impact of a caring role on well being.

Both generic and carer specific outcomes will be considered in the following chapters. The next chapter will consider generic outcomes relating to both psychological well-being and to physical well-being. It will then go on to consider population specific outcomes, collected under the concept of 'carer burden', and including outcomes relating to the care recipient. Finally, chapter 4 will move on to examine social functioning and support.



## **Chapter 3: Concepts of Well-Being among Carers**

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## **1. Psychological Outcomes**

### **1.1 Assessing psychological well-being**

A large proportion of the research carried out in the area of informal caregiving has included non-population specific measures of psychological distress and morbidity. Psychological well-being, is however, a wide ranging and often vaguely defined construct, and many options present themselves concerning its conceptualisation and assessment.

In considering the conceptualisation and assessment of psychological well-being, it may be worth starting with a note of pessimism. It has been argued that, historically, conceptions of psychological state have had little theoretical basis and, as a consequence, measures have had unsatisfactory validity (Ryff, 1989). In fact, Bradburn (1969) in discussing the central question of how to select dependent variables in studying "difficulties in living" stated:

"There are no clear-cut criteria for making this choice. Indeed, much of the art of scientific investigation lies in the choice of the variables to study; and the difference between success and failure appears to lie more in the realm of intuition and luck than in scientific enterprise." (p. 6)

#### **1.1.1 The role of subjective meaning**

An important decision facing researchers wishing to examine psychological well-being is the extent to which subjective meaning and personal reporting directs the operationalisation of the concept. Taken at face value, the concept of psychological well-being may seem to imply a state of personal and subjective experience, only directly accessible by the individual themselves. However,

assessments of psychological well-being in practice often attempt to define the concept objectively and quantify it as much in terms of an observer's assessment as by reference to an individual's self report. For example, in mental health care, assessments using scales such as the Brief Psychiatric Rating Scale (Overall & Gorham, 1962) will often rely as much (if not more) on an assessor's interpretations and observations than those of the patient. Diagnoses are made and conclusions are often drawn, rightly or wrongly, that contradict the self-reporting of the patient (most saliently in cases where the mental health legislation is invoked so as to treat a patient against his or her wishes).

A commonly used interview schedule in studies of treatment outcome is the Hamilton Rating Scale for Depression (HAM-D; Hamilton, 1960). The HAM-D is a 21-item rating scaled used to systematise clinical observations of features related to depression. A trained observer completes it after a 30-minute clinical interview that assesses symptoms of depression. Typically, a 'break score' of 18-20 is used to differentiate persons with probable depressive disorder. The HAM-D, by rating psychological well-being on the basis of a trained observer's ratings, to some degree avoids the subjectivity inherent in self report measures.

However, it is debateable whether this is an advantage. In its avoidance of respondents' subjective responses, the HAM-D can be seen as missing the very essence of psychological well-being, that is, subjective experience and personal meaning. In line with this, the HAM-D has been criticised for its emphasis on behavioural symptoms and somatic complaints, as well as its neglect of self-reported feelings of distress (Maier & Philipp, 1985).

Self-report measures of psychological well-being, on the other hand, embrace the subjectivity inherent in the assessment of psychological well-being. This may be seen as an advantage in the light of evidence that there is substantial disagreement between clinicians and clients with regard to overall identification of psychological well-being (Kalpakjian et al 2002).

Whatever the relative conceptual value of observational versus self-report instruments however, there is no doubt that it is the latter that is more widely used in research. For example, Schulz et al (1995) identified the main approach to assessing the extent of psychological morbidity among carers within the literature to be that of self-report. However, whether this is a result of an effort to tap into subjective experience, or the fact that self report measures are far less expensive and quicker to administer than interview schedules, is unclear.

There is now a plethora of measures of self-reported psychological well-being instruments currently available. In their review, Schade et al. (1998) identified over 40 different instruments that have been used within non-clinical (primary care) samples. Of these, however, the majority have not been widely used and little is known about their validity or reliability. Research has tended to focus on a small sub-group of scales of scales that have now become well known within health care research.

Schade et al. (1998) identified five instruments that were mentioned in 20 percent or more of the studies in their review: the Geriatric Depression Scale, the General Health Questionnaire (GHQ), the Beck Depression Inventory (BDI), the General Health Questionnaire (GHQ), the short version of the Zung Self Rated Depression Scale (SDS), and the Center for Epidemiologic Studies Depression Scale (CES-

D). These, along with several other scales that have become widely used in research, are compared in table 3.1.

**Table 3.1: Self-report instruments assessing psychological well-being**

<b>Scale</b>	<b>Subscales</b>	<b>Comments</b>	<b>Reliability / Validity</b>
<b>Beck Depression Inventory (Beck et al., 1961)</b>	Has been found to include three to seven factors.	The content of the BDI was obtained by consensus from clinicians regarding symptoms of depressed patients (Beck et al., 1961).	Internal consistency from .73 to .92 with a mean of .86. Test - test reliability from .48 to .86, depending on the interval (Groth-Marnat 1990). Sensitivity: 100%. Specificity: 89% / above 15*
<b>Center for Epidemiologic Studies Depression Scale (Radloff, 1977)</b>	Four subscales: negative affect/mood, positive mood or well-being; somatic; interpersonal	Well used and tested among community based samples, including elderly samples (Beekman et al., 1997).	Internal consistency at least 0.85 across numerous studies (e.g., Badger et al., 2000, 2005). Good test-retest reliability Test-retest reliability adequate (Hann et al.1999). Sensitivity: 89% Specificity: 70%/above 15
<b>Geriatric Depression Scale (Yesavage, Brink, Rose et al., 1982)</b>	Positive and negative affective domains of depression	Developed specifically to discriminate the pattern of depressive symptoms from the general characteristics of elderly populations.	Internal Consistency: .94 2. Test-retest reliability coefficient: .85 (from authors). Sensitivity: 92% to 97%. Specificity: 100%/above 13
<b>Zung Self Rated Depression Scale (Dugan, McDonald, Passik, et al 1998)</b>	Four factors: cognitive, manifest depressed mood factor, somatic (eating related) and somatic (non-eating related) (Passick et al, 2001).	Patient specifies the frequency with which the symptom is experienced (that is: a little = 1, some = 2, a good part of the time = 3, or most of the time = 4). [	Internal consistency reported > 0.84 (Passik et al., 2001). Sensitivity: 97% Specificity: 63%/above 49
<b>General Health Questionnaire (GHQ)</b>	Usually represented as a single score of psychiatric symptoms	Developed as a as a screening instrument in community settings, primary care, and medical out-patients.	Internal consistency for GHQ-60, GHQ-30, and GHQ-12 range from 0.82 to 0.93. Test-retest between 0.51 and 0.90

<b>Profile of Mood States (McNair, Lorr, &amp; Droppleman, 1992)</b>	Six subscales: tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, confusion-bewilderment	Developed to serve as a brief measure of transient mood states among adolescents and adult populations.	Internal consistency 0.80 (Koopman et al. 2001).
<b>Hospital Anxiety &amp; Depression Scale (Zigmond &amp; Snaith, 1983)</b>	Severity of depression and anxiety	Developed in general medical hospital outpatient setting.	Internal consistency for HADS-A varied from .68 to .93 (mean .83) and for HADS-D from .67 to .90 (mean .82). The Anxiety and Depression scales are moderately correlated (.53). (Crawford et al. (2001).

\* (All data on specificity and sensitivity of scales from Sharp & Lipsky 2002)

### 1.1.2 Adaptative and Maladaptive Concepts

Even a brief examination of measures used in previous work on 'psychological well-being' makes clear that there has been a 'negative bias', and that much more attention has been devoted to human unhappiness and suffering than to the causes and consequences of positive functioning. That is to say, the dimensions of psychological well-being of interest, especially in empirical health services research, have been those loaded towards negative experience and emotions that dip below a 'normal' state rather than those that imply a rise above it.

Research into the experience of caregivers has provided no exception and by far the most common outcome in the informal caring literature is depressive symptomatology. Indeed, symptoms of depression are second only to the population specific concept of carer burden in terms of utilisation in studies of carers (Sherwood et al, 2005).

The focus on negative or 'maladaptive' psychological states has been criticised. For example, Ryff (1989) saw the neglect of positive functioning and the reliance on negative concepts as a consequence of the lack of theoretical underpinning in the study of psychological well-being. She argues that, traditionally, instruments were developed for other purposes, and then these then became the 'gold standards' and continue to serve as outcome variables in studies aimed at identifying factors that influence well-being and predicting who has it.

One drawback of the traditional measures of 'negative' well being is that they may make 'floor effects' more likely when research involves samples with initially low levels of, say, depression or anxiety. This in turn may lead to the positive effects of intervention being obscured.

Another criticism is that traditional measures of psychological well-being ignore the many 'positive' outcomes of caring. For example, in a recent study, Kim et al. (2007) identified six domains of positive outcomes, including acceptance, empathy, appreciation, family, positive self-view, and reprioritization. This study revealed that some of these domains were better related to adjustment to the caring role than others. Specifically, coming to accept what happened and appreciating new relationships with others related to greater adaptation.

It may be an oversimplification, however, to view the traditionally assessed psychological symptoms of depression or anxiety as simply 'negative' and 'maladaptive' – particularly in the context of highly demanding living conditions such as those intrinsic to informal caring. From an evolutionary perspective, it can be argued that these symptoms are actually adaptive in situations where continued effort to pursue a goal may be dangerous or futile (such as attempting

to take on too many tasks without adequate resources). As Nesse (2000) argues, "Just as anxiety inhibits dangerous actions, depression inhibits futile efforts". Such symptoms may also act as an alarm bell, helping to alert both the individuals themselves to an impending critical situation, and also helping to notify others that support is needed.

Arguing that symptoms of depression or anxiety are 'adaptive', however, is not the same as saying they are 'positive' outcomes. Their alleviation is of course desirable and indicates a move away from the situation of which they warn, that is, a state complete 'breakdown' of mental or physical resources and a point at which symptoms take on 'clinical' significance.

### **1.1.3 Clinical Significance**

Poor psychological well-being does not always imply pathology, and indeed, fluctuations in well being can be viewed as part of 'normal' and healthy experience. The choice of instrument will therefore be influenced by whether the intention is to capture the effects of circumstances that may lead to transient alterations in mood states (such as is case with the Profile of Mood States instrument) or whether it is to focus on consequences at a 'clinical' level for the individuals concerned (as with the Beck Depression Inventory). Inherent in the latter category of instrument is the concept of 'caseness', which would be indicated if an individual scores over and above a specified 'cut-off' score.

The need for clinically significant outcomes in carer research was highlighted by Schulz et al (2002). They observed that, although many studies with carers have reported statistically significant effects on a broad range of outcomes, only a small

proportion of these findings related to clinically significant outcomes. The need for clinically meaningful measures is also highlighted by the abundant evidence pointing to a clinically significant effect of caregiving on psychological well-being, and particularly depression (discussed in the next section).

Striving for clinical significance in caregiver research outcomes, however, should not override attention to whether a measure is suitable for community (non-clinical samples). This point can be illustrated by considering the Beck Depression Inventory (BDI). The BDI has been reported to have good reliability and validity in several populations, including the elderly (Gallagher et al., 1982). However, one major consideration is that the BDI was developed based on the author's observations of clinically depressed patients undergoing psychotherapy. As discussed by Bowling (1991), the BDI is a measure of severity of depression once a clinical diagnosis has been made. That is, it is unsuitable for use in the absence of a prior diagnosis.

Other measures also have limited applicability in community samples of carers. One example is the Geriatric Depression Scale (GDS). The GDS was developed to discriminate the pattern of depressive symptoms among older people from the general characteristics of the elderly population and was validated among patients hospitalised for depression (Yesavage et al, 1983).

Other scales have been specifically designed to have applicability among community samples while also being able to indicate levels a likely clinical diagnosis of depression. The CES-D, for example, is an extensively used 20-item scale of depressive symptomatology over the past week. The scale was designed to assess symptoms of depression in the general (i.e.- non-clinical) population.



## **1.2 Review: Psychological well-being among carers**

Poor psychological well-being is commonly found within the caregiver population as a whole, with levels reaching far beyond those found in the general population (Schulz et al., 1995). Indeed, a recent review of previous literature by Cuijpers (2005) makes clear that prevalence and incidence of depressive disorders are increased in carers. The author examined ten studies with 790 carers included. The combined findings revealed that a total of 176 participants (22.3%) had a depressive disorder (prevalence range from 0.15-0.32). Notably, in six of the studies reviewed by Cuijpers (2005), carers were compared to a matched control group. The relative risks of a depressive disorder in carers ranged from 2.80-38.68 (with all the risk ratios being significant).

While there has been relatively little work conducted on other aspects of psychological well-being, there is some evidence that the effects of caregiving are not limited to depressive disorder and symptomatology. For example, carers have been found to report higher levels of both anxiety and hostility than matched controls (Anthony-Bergstone et al. 1988), as well as to score above the GHQ cut off point for psychiatric caseness far more frequently than would be expected according to published prevalence rates among community samples (Schulz, et al, 1990).

It should be noted that an increased risk of psychological morbidity has also been consistently found in studies that go beyond self-report approaches to assessment. Using the Structured Clinical Interview for DSM III-R, Dura et al. (1991) found the prevalence of depressive and anxiety disorders among carers to be 18% and 9% higher respectively than in a matched, non-carer control group. Using an alternative approach, Baumgarten et al.(1992) compared carers and

non-carers on the use of psychotropic medication. The prevalence of medication use among carers was almost double that within the comparison group (26% versus 14%).

## **2 Physical Outcomes**

### **2.1 Assessing Physical Outcomes**

In view of the substantial body of evidence linking adverse life events and psychological stressors to physical health, one may expect that a severe and chronic stressor such as an informal caring role would have equally severe physical consequences. Many researchers have suggested that the combination of ongoing psychological stress and physical demands may compromise the physiological functioning of carers and increase the risk of physical morbidity (Vitaliano et al, 1997).

Vitaliano et al. (1997) see 'loss' as fundamental to these effects. They argue that carers may experience prolonged anticipatory bereavement over lost aspects of their relationships with their care recipients, and bereavement is positively associated with physical illnesses (Kaprio et al. 1987), health care utilisation (Prigerson et al., 1997) and mortality (Goldman et al. 1995).

In the assessment of the physical outcome from intervention various options present themselves. Most commonly, assessments of physical health status focus on individuals' personal reports of their health and how the experience of

physical 'events' impinges upon well being (Hunt, 1988). Another approach is to employ direct assessment of physiological functioning.

### **2.1.1 Subjective versus Objective Reports**

As in the case of psychological well-being, an important issue in conceptualising and operationalising physical health outcomes is the place of subjectivity and the value of self-report. Decisions must be made relating to the extent to which individual perception and meaning is to be filtered out of assessment procedures.

There are clear advantages to assessing physical health outcomes via self-ratings. One such advantage is the relative simplicity of this method (in comparison to physiological assessment for example). Self-rated health outcomes can be incorporated easily into test batteries at very little cost, and minimal training or instruction (for either interviewer or respondent) is required in their administration. This approach also has the advantage of representing a clear end point and arguably has high 'face validity'. That is to say, the level of symptoms or illnesses experienced by an individual will almost certainly be of direct and immediate saliency to them (unlike, for example, the level of a particular hormone). Thus, self-reported health may be argued to be closer in conceptual terms to the quality of life of the individual.

The method of asking participants to report on their own health may, however, be criticised for the degree of subjectivity involved. Indeed, the extent to which symptom or illness reports are truly an index of physical outcome rather than a psychological outcome is open to debate. Complaining about these physical correlates has been suggested to be a good marker of depression rather than physical ill-health (somatising) (Stansfeld et al, 1993).

One alternative to assessing physical condition that may be seen as avoiding the problem of patient subjectivity is to take data from medical notes or clinician interviews. However, there are also problems inherent in assumptions about the objectivity of such data. For example, Bowling (1997) points to the lack of agreement between patients and doctors on the success of treatment (eg- Orth-Gomer et al., 1979).

In attempts to return the emphasis back to the patient, while avoiding the subjectivity of direct symptom reporting, studies of interventions in many areas have examined records of health care utilisation as an outcome. This has been a common outcome in interventions ranging from those aimed at problem drinkers (Dinh-Zarr et al, 2004) to work on asthma management plans (Fricker, 2005). The assumption here is that a higher level of health care service use indicates greater experience of physical ill health. This assumption is debateable however in the case of carers. For example, one study found that while carers were more likely than non-carers to report more physical symptoms, as well to be more likely to report having two or more current health conditions, carers and non carers did not differ significantly with regard to the number of outpatient medical visits (Scharlach,et al. 1994). Health service utilisation by carers is, in fact, likely to be determined by a number of factors other than physical well-being. These include the unavailability of substitute care for the care-recipient, as well as care recipient reluctance, lack of knowledge of services or difficulties in the process of applying for services (Brodaty et al. 2005).

### **2.1.2 Clinical versus Symptomatic Outcomes**

Another issue in selecting outcomes relating to physical health is the extent to which they reflect diagnosable, clinical conditions (eg – Irritable Bowel Syndrome) or more transient symptoms (eg – headaches) that may or may not be part of an underlying clinical condition.

One advantage of examining clinical conditions as outcomes is that they may be of greater significance to the overall well-being of the person than individual symptoms. For example, while symptoms such as stomach pains may come and go for most people, and may not impact significantly on one's life, a diagnosis of irritable bowel syndrome is almost certainly going to challenge an individual's personal resources over a prolonged period of time and represent a 'significant' concern.

The problem with employing clinical conditions as outcomes in research, however, is that they often develop gradually, sometimes over many years. As such, they lack sensitivity to change and, while they may be appropriate outcomes for longitudinal studies over several years, or for cross-sectional analyses of illness prevalence, they will rarely be appropriate for assessing the impact of singular, short-lived interventions. Assessments at the level of physical symptoms, however, may be more sensitive to short-term intervention effects since large and extensive physical changes do not need to occur for change to be measurable.

## **2.2 Direct Physiological Assessment**

Another way of attempting to avoid subjective bias (of the part of either the patient or clinician), as well as any extraneous influences on outcome (like in the case of

service utilisation) is to directly assess physiological functioning. Prolonged or repeated activation of certain physiological systems is thought to place individuals at risk for the development of a wide range of physical and mental conditions. Three interrelated physiological systems in particular have been of interest in research concerned with indicators of the stress response: the autonomic nervous system (often operationalised via examination of cardiovascular responses), the immune system, and endocrine functioning.

### **2.2.1 Cardiovascular Outcomes**

The cardiovascular system plays a pivotal role in the pattern of physiological responses to psychologically stressful circumstances. A central function of the cardiovascular system is to maintain a sufficient blood flow in the face of changing requirements and conditions. Cardiovascular responses to psychological stress may include a change in blood pressure, heart rate, or the electrophysiological functioning of the heart. Rather than being part of a consistent pattern, cardiovascular responses to stress are likely to differ according to the nature of the demands encountered (Krantz & Falconer, 1995).

A lot of research has focused on the idea that exaggerated cardiovascular responses to stress (ie – high ‘reactivity’) predict the onset and course of diseases beyond that provided by standard risk factors. In a recent review, Treiber et al. (2003) evaluated the evidence for the hypothesis that cardiovascular reactivity can predict the development of preclinical (elevated blood pressure, ventricular remodeling, carotid atherosclerosis) and/or clinical cardiovascular disease states. From the studies reviewed, it was evident that the predictive value of cardiovascular reactivity depends to some extent on health status at baseline. That is, in initially healthy samples there was little evidence of a relationship

between reactivity and clinical outcomes, whereas in samples with pre-existing coronary heart disease or hypertension, there was a strong, a positive relationship between reactivity and subsequent disease states.

Treiber et al (2003) also found an effect of methodology on the predictive value of cardiovascular responses. In particular, they conclude that studies with follow-up periods over 20 years or more do tend to find blood pressure responses to be predictive of subsequent essential hypertension in initially healthy samples. However, studies employing shorter-term follow-up periods show less consistent findings.

### **2.2.2 Immunological Outcomes**

The immune system is the body's defence against infectious and malignant disease. The immune response, which may be triggered by antigens such as viruses, bacteria or allergens, takes two main forms- the humoral immune response and the cellular immune response. The former response, humoral, involves B-lymphocytes that produce antibodies and immunoglobulin. These in turn react with antigens with great specificity. The cellular response, on the other hand, is centred on T-lymphocytes and is crucial to the defence against intercellular viruses and cancer cells.

A high and / or prolonged level of psychological stress is thought to have an effect on immune functioning. In a recent study, for example, Mills et al (2004) examined the effects of being a spousal carer of a patient with Alzheimer disease (AD) on the lymphocyte beta(2)-adrenergic receptor. They compared spousal carers and non- carers, as well classifying the carers group as either vulnerable or

non-vulnerable on the basis of the amount of care required by the patient relative to the amount of respite the carers received during the previous 6 months. They found that vulnerable carers had reduced beta(2)-adrenergic receptor sensitivity and density when compared with their non-vulnerable counterparts or with non-caregivers.

While immunological measures may have some value in caregiver research, however, there are some issues to consider. First, from a purely practical point of view, employing immunity related measures can be expensive. As Kiecolt-Glaser & Glaser (1995) point out, the costs for even a small pilot study can be very high when the required supplies, laboratory costs and human resources are taken into account. Second, and particularly relevant to stress-related research, immunity related assessment can be very invasive for the research participant and usually involve the obtaining of repeated blood samples. This creates the possibility that the assessment process can become a stressor in itself and obscure any effects on the variables of interest. Third, most (although not all) measures related to the immune system cannot be self-administered by research participants, thus requiring the presence of a researcher, which in turn creates an unnatural situation that may influence findings. Use of an in-dwelling catheter is possible in some cases, although this is likely to be expensive and impractical for individuals who have a demanding physical role such as carers.

Another issue relating to the link between stress and immunity is that it is likely, in most cases, to be an indirect link and mediated by stress hormone activity. In a recent review, Calcagni & Elenkov (2006) examined evidence indicating that glucocorticoids and catecholamines (stress hormones) inhibit systemically IL-12, TNF-alpha, and INF-gamma, and upregulate IL-10, IL-4, and TGF-beta



production. Therefore, the role of stress hormones in inhibiting or increasing of cytokine production may represent an important mechanism by which stress affects various immune-related diseases.

### **2.2.3 Endocrinological Outcomes**

It may be that, of the three physiological systems mentioned earlier in this section, it is endocrine functioning that lies at the most fundamental level of the stress response. This is because the effects of stress on both cardiovascular functioning and immunity may to some extent be mediated by neuroendocrine mechanisms (Calcagni & Elenkov, 2006).

#### **2.2.3.1 The Endocrine System**

The endocrine system is a control system of glands that secrete hormones. Hormones are effectively chemical "messengers" that circulate within the body via the bloodstream to affect distant cells within specific organs. These cells then interpret these messages and act on them. The major glands of the endocrine system are the hypothalamus, pituitary, thyroid, parathyroids, adrenals, pineal body, and the reproductive organs (ovaries and testes). The pancreas is also a part of this system in that it has a role in hormone production as well as in digestion.

The endocrine system works by a series of 'signals'. For the hormones that are regulated by the pituitary gland, a signal is sent from the hypothalamus to the pituitary in the form of a "releasing hormone," which stimulates the pituitary to secrete a "stimulating hormone" into the circulation. The stimulating hormone then signals the target gland to secrete its hormone.

The whole process is regulated and kept under control by a 'feedback' system. As the level of a particular hormone rises in the circulation, the hypothalamus and the pituitary gland shut down secretion of the releasing hormone and the stimulating hormone, which in turn slows the secretion by the target gland. This system results in stable blood concentrations of hormones.

#### **2.2.3.2 Cortisol**

One of the central 'routes' by which the endocrine system exerts its action is the hypothalamic pituitary adrenal (HPA) axis. As its name suggests, the HPA axis comprises three endocrine glands, the hypothalamus, the (anterior) pituitary, and the adrenal gland cortex.

The purpose of the HPA axis is to increase the amount of usable energy in the body and direct it to the places it is most needed. The HPA axis begins in the hypothalamus, which is located at the base of the brain. The hypothalamus secretes corticotropin releasing factor (CRF), which in turn binds to specific receptors on pituitary cells. This in turn produces adrenocorticotrophic hormone (ACTH). ACTH is then transported to its target in the adrenal gland cortex and stimulates the production of cortisol.

Cortisol is a glucocorticoid and is known to have many effects on physiological functioning. For example, it stimulates the creation of glucose to ensure an adequate fuel supply, stimulates protein catabolism to release amino acids for use in energy production, acts as an anti-inflammatory agent (synthetic cortisol preparations are used for anti-inflammatory purposes) and it generally depresses immune reactions.

Chronically stressed individuals may have continually elevated cortisol levels due to overactivity of the hypothalamic pituitary adrenal axis (Vedhara et al., 1999). A prolonged increase in daily cortisol secretion levels may have significant metabolic cost to the individual, with prolonged elevation potentially leading to diabetes, hypertension, arterial disease, amenorrhea, impaired tissue repair and immunosuppression (Brindley & Roland, 1989). More recently, elevated basal cortisol levels have also been suggested to cause hippocampal damage, with hippocampal atrophy correlating strongly with both the degree of cortisol elevation over time and current basal cortisol levels (Lupien et al. 1998).

## **2.3 Review: Physical well-being among carers**

### **2.3.1 Self-Reported Health**

While the findings of research investigating the consequences of caring in terms of psychiatric morbidity have shown consistent effects, there has been less consensus over the years concerning physical health outcomes (Schulz et al. 1995). However, a recent meta-analysis by Vitaliano et al. (2003) examining the effects of a caring role across 11 health categories, demonstrated that caregivers do exhibit a slightly greater risk for health problems than non-caregivers overall, but that this overall effect is diminished by the fact that the specific health category assessed moderates the physical impact of caring.

The authors performed a meta-analysis of 23 studies, over a 38-year period, which compared 1,594 carers of persons with dementia to 1,478 non-carers who

were similar in their distributions of age and sex. They examined a total of eleven health categories: five categories of self-reported health and six categories of direct physiological measurement.

In Vitaliano et al.'s (2003) analysis, the impact of a caring role on global health indicators was greater than that for the other reported health categories. This is consistent with previous studies that have found carers to rate their physical health as significantly poorer on global, single item self rated health measures than non-carers (Schulz et al., 1995).

If we examine other approaches to assessing self-reported health, findings become less consistent. For example, Vitaliano et al (2003) reported that health care utilisation was the least likely self report outcome to show a difference between carer and non-carer samples, and previously, in a study of chronic conditions, Baumgarten et al., (1992) found the level of illness reported was comparable between carers and non-carer samples.

One reason for the lack of consistent evidence for some physical health effects of caring may be related to time scales. It may simply be that while psychological effects may emerge rapidly in response to the stress of caring, physical effects takes more time to become evident. Reports of depressive or anxiety symptomatology, for example, may be motivated in part by a respondent's bleak view of his or her future. Thus, there may be no time lag required between a stressor and a measurable psychological reaction. The impact of a stressor upon physiological functioning however may need to be persistent and chronic, possibly for many years, before that altered physiological functioning (eg- a rise in blood pressure) is manifested in terms of reported illness (hypertension, CHD).

Furthermore, it may be that the stressors associated with caregiving do not always precipitate an illness event per se, but do aggravate existing vulnerabilities.

We may address the issue of a time lag between the chronic stress of caring and the manifestation of physical deterioration in several ways. The first, and most obvious, is to conduct analyses over longer periods of time. As Schulz et al., (1995) point out, one glaring omission in the carer literature is that of prospective studies.

A study carried out by Schulz & Beach (1999) goes some way to address this imbalance. This research investigated the role of caring as a risk factor for all cause mortality. A large sample of 392 spousal carers and 427 matched non-carers (all living with their spouses) were followed up over a 4 year time period. Results indicated that carers experiencing strain were 63% more likely to have died at follow up than non-carer controls.

### **2.3.2 Physiological Outcomes**

The other way of addressing the time lag between the stress of caring and the manifestation of physical morbidity may be to examine outcomes that capture the immediate, *in situ*, physical effects of caring. In Vitaliano et al.'s (2003) meta-analysis of the effects of caring, physiological categories included antibody responses to vaccination and viruses, enumerative cellular immunity (counts of immune-cell markers), functional cellular immunity (ability to fight tumours and viruses), cardiovascular measures (e.g., blood pressure), metabolic measures (e.g., glucose levels, weight), and levels of stress hormones.

### **2.3.2.1 Cardiovascular Outcomes**

In terms of the cardiovascular system, caregivers have exhibited significant increases blood pressure levels when in the presence of the care recipient (King et al.1994) as well as a greater likelihood of meeting criteria for borderline hypertension than non-caregivers (Shaw et al. 1999).

Of particular relevance to the caregiving population is blood pressure, with recent research indicating that the hazards of meeting criteria for borderline hypertension are greater for caregivers than for controls (Shaw et al. 1999).

### **2.3.2.2 Immunological Outcomes**

Impaired immune responses have also been observed among caregivers, with increases in antibody titers in response to influenza virus vaccinations diminished compared to controls.

For example, Kiecolt-Glaser et al. (1996) found that carers showed a poorer antibody response following vaccination relative to non-carers as assessed by both enzyme linked immnosorbent assay (ELISA) and hemagglutination inhibition. They also had lower levels of in vitro virus-specific-induced interleukin 2 levels.

### **2.3.2.3 Endocrine Outcomes**

In Vitaliano et al.'s (2003) analysis, however, the evidence was particularly strong for an effect of a caring role in relation to stress hormones. The review found that found caregivers had a 23% higher level of stress hormones compared with non-

caregivers. Taking cortisol as an example, one study found on repeated follow-ups that overall daily cortisol secretion was significantly higher in a group of spousal caregivers as compared to controls (Vedhara et al. 1999).

In situations of chronic stress, it may be morning and evening cortisol levels that are the most revealing. For example, in Vedhara et al.'s (1999) study, the greatest difference between the groups was observed between 0800-1000 hours. Consistent with this, in another study concerned with the stress of long-term unemployment, unemployed subjects had a diurnal pattern of cortisol excretion with relatively higher morning and lower evening levels than employed controls (Ockenfels, et al, 1995). More recently, in a study of job strain (high demands, low control), cortisol was significantly elevated at 8:00 to 8:30 hours in the high job strain group but not at later times of the day or evening (Steptoe et al. 2000). Finally, Adam et al (2006) observed that same-day feelings of tension and anger among a sample of older adults were associated with flatter diurnal cortisol rhythms, primarily because of their association with higher same-day evening cortisol levels. In this study, findings suggested that momentary effects of psychological stress may cumulate across the day to result in higher bedtime cortisol and a flatter diurnal cortisol slope, a sort of biological signature of a "bad day."

For caregivers, there may be a number of reasons why the effects of stress on cortisol is most pronounced in the morning. When caring for a relative at home, mornings are often the most stressful part of the day, in which several difficult tasks must be completed in a relatively short space of time (ie- getting the patient out of bed, bathing the patient, breakfast). The difficulty of these tasks is likely to rise with the level of dependency from the care-recipient, not only due to a lack of

co-operation in getting things done, but also the greater likelihood that sleep was disturbed the previous night. At other sampling times, the care recipient may have been more likely to be attending a day centre, being looked after by a care assistant, or asleep in the case of late samples. Thus, the immediate physiological impact on the caregiver of their role may be diminished at these later times.

The pronounced effect of caregiver stress on morning cortisol levels may not be completely attributable to factors relating to caring tasks however. As mentioned above, other studies have found elevated cortisol levels among chronically stressed individuals only in morning samples. In these cases, however, the chronic stress was due to unemployment and job strain, rather than caring. Unemployment in particular, although stressful, is not likely to lead to heightened morning activity.

### **3.1 Conceptualising 'carer burden'**

As already mentioned in chapter 2, while carers may be 'ordinary' people, their experiences go beyond that of 'ordinary' life. Therefore, while it is true that concepts such as depression and physical health are relevant to carers just as they are relevant to the rest of us, such concepts may fail to tap into the extraordinary experiences involved with a caring role. No matter how well validated a more global measure of well-being may be, they often fail to address many specific issues relevant to the care of a chronically-ill person (eg-manipulation by the care-recipient). This may be partly why caregivers have been



found to report lower levels of stress on generic self-report instruments than when alternative assessment methods are used (Haley et al, 1987).

Many writers on caregiver burden have called for outcome measures that better reflect the goals caregivers have for themselves and their special circumstances (Zarit & Toseland, 1989). They argue that it is necessary to supplement generic measures of well-being with instruments that cover caregiving issues more specifically (ie- measures of 'carer burden').

The concept of 'carer burden' was viewed initially as a one-dimensional phenomenon, but has more recently been expanded to further acknowledge the importance of subjectivity in carers' experience, and the emotional impact that a caring role can have. Accordingly, from the mid 1980's most researchers conceptualized burden along two dimensions: subjective and objective.

## **3.2 Objective Burden**

### **3.2.1 Excluding non-specific factors**

The 'objective' burden all of us experience in life will be a function of many factors. These may include the nature of our occupation, our financial situation, our physical condition, our intellectual abilities, and the relationships we have with others.

All these, of course, pertain to carers as much as to the rest of the population and will be major determinants of their overall health and well being. However, in conceptual terms it can be argued that, since these factors do pertain to

individuals lives whether they are carers or not, that it would be inappropriate to consider them as elements of a population specific construct such as 'carer burden'. Rather, it may be more appropriate to consider them as important, but external mediating factors that may attenuate or exacerbate the effects of a caring role.

An objective factor that can be considered as truly 'carer-specific' is the condition of the care recipient. The nature and severity of the condition will determine dependency, which from the perspective of the carer will in turn determine what needs to be done, in what circumstances, and how often. Indeed, in the case of a full-time carer, this factor represents a substantial and highly salient part of one's objective environment. This is now discussed.

### **3.2.2 Condition of the care recipient**

Any medical condition can be seen as having a range of dimensions along which its symptoms and consequences may be assessed. For example, to what extent does the condition cause pain, restrict mobility, disfigure or interfere with one's independence? The answers to these questions will not only have consequences for the person living with a particular condition, but also for those who provide care to them.

The condition of a cared for person is by no means limited to the physical ability (or inability) to walk or bathe oneself. While informal care is provided to individuals with a wide range of illness, two major dimensions of impairment can be identified and examined, that is, physical and mental. Particularly in the case of mental impairment, behavioural problems are among the core symptoms of many illnesses requiring care. These can range from night-time activity that

disturbs the sleep of the carer, to acts of hostility and aggression towards either the carer, or other family or friends. Indeed, changes in personality and behaviour are intrinsically linked. Of course, in many conditions requiring ongoing care, both physical and mental impairment can co-exist creating a combination of stressors for the carer.

### **3.2.3 Conceptualising Impairment and Disability**

From a traditional, medical model, if a person has an impairment, then disability inevitably follows. From this perspective, the concept of being 'disabled' becomes more of an adjective than a verb, that is, it is something that an individual 'is' – not something that happens to them. In this sense, the medical model makes no distinction between impairment (for example when illness or injury compel a person to use a wheelchair) and disablement (as when lack of a wheelchair ramp denies that person access to a public place).

In reaction to this view, the 'social model' of disability emerged. This approach was pioneered by the Union of the Physically Impaired Against Segregation (1975), who saw disability as...

*"...the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from participation in the mainstream of social activities."*  
*Fundamental Principles of Disability, 1975*

The central aspect of this social model is that disability is not an inevitable consequence of impairment, but rather that disability is the discrimination that

people with impairments encounter in society, created by physical, environmental, organisational and attitudinal barriers which exclude disabled people from full participation (Shakespeare, 1992). From this perspective, therefore, one may make the case that disability is socially constructed and not a direct consequence of a condition that is linearly related to the degree of impairment.

In response to these considerations *the International Classification of Functioning, Disability and Health (ICF)* was developed by the World Health Organization. The ICF illustrated a clear shift: from describing disability and impairment synonymously or simply in negative terms to describing body structure, functioning, activities and participation in an objective way.

In the ICF The general term *functioning* refers to all body functions, activities and participation while the term *disability*, is understood to encompass the interaction between impairments and externally imposed activity limitations or participation restrictions.

#### **3.2.4 Physical Impairment**

A physical disability can often create a physical strain for a carer. Lifting, bathing and manoeuvring of wheelchairs etc can create an ongoing physical pressure that can easily result in physical morbidity for the carer. This morbidity may occur over time, or suddenly due to an injury while performing a caring task. Brown & Mulley (1997) found that over 75% of their sample of carers reported having injured themselves whilst lifting and handling their dependents. One quarter of these injured carers had been temporarily unable to continue caring as a result. Very few carers reported receiving any instruction in safe manual handling.

The physical strain of caring for someone with a physical disability can to some degree be alleviated by the installation of apparatus such as hoists and chair lifts as well as major adaptation to bathrooms and bedrooms. However, there is also an emotional frustration that comes with such drastic measures. The carer will experience his or her home completely transformed. The sense of one's home coming to resemble a hospital can be a shattering experience, as well as leading to a reluctance to entertain friends or family. The installation of equipment can also be financially draining, with hoists or lifts often costing thousands of pounds, and local authority subsidy frequently being scarce.

### **3.2.5 Mental Impairment**

Behavioural and personality changes are acknowledged as some of the earliest changes among persons with chronic illnesses such as dementia (Petry et al. 1988). They are also some of the most common problems, with studies suggesting that approximately 80% of people with dementia exhibit one or more troublesome behaviours (Burns et al, 1990).

A mental impairment, often more than physical illness, adds to the stigma of the caring experience. The behavioural problems that often come with mental health problems can cause great distress and embarrassment for the carer, family & friends, as well as the cared for person themselves. Twigg (1992) refers to negative impact mental disability can have on a carer's social life. For example, people may not want to visit the home for fear of hostility from the cared for person and indeed carers of people with mental disabilities are often reluctant to invite people to their home for the same reasons (Tsang et al., 2003).

Aside from the stigma involved in the experience of caring for mental impairment, there is also a sense of loss or bereavement. Carers often report feeling that they have lost the person they once loved and that the person they are caring for is like a stranger. This sense of loss may be particularly acute in cases where the cared for person no longer recognises the carer (Sanders & Adams, 2005).

Behavioural problems are also often problematic simply because many will occur in the middle of the night. Indeed, it may be the fact that some behavioural problems do manifest themselves at night that makes them so stressful.

For example, ongoing behaviours such as screaming and wandering are almost certain to chronically affect carers' sleep. Research has indicated that the prevalence of sleep dependency among caregivers may be high, as well as have an impact on well-being. In a recent study, Happe & Berger (2002) examined sleep among 106 Parkinson's disease patients and their spousal carers. They found frequent sleep disruption was reported by 27% of all spouses, and that poor night-time sleep in carers was related to poor sleep in patients (although causality here may be bi-directional). There was also a significant association between poor sleep and carers' depressive symptom severity as assessed by the CES-D. In another study of 51 carers, 95% expressed severe sleep problems. There was again a significant link between sleep and carer depression (Carter & Chang, 2000).

Most of the evidence examining the effects of care recipient condition on carer burden pertains to behavioural problems rather than functional impairment or cognitive functioning. In their review, Schulz et al., (1995) found only one of ten studies suggested a link between functional impairment and carer depression and

only two from eight studies indicated an effect of cognitive impairment. However, nine out of ten studies reported a significant relationship between behavioural problems such as wandering, destroying property etc and carer depression. Other studies have added to support to the view that behavioural problems are a major factor in determining carers' well-being (Pornari et al., 2006, Clyburn et al, 2000).

More specifically, it may be deterioration in behavioural problems, and changes in personality, that have an impact on carers. A longitudinal analysis followed 64 carers over a year examining changes in problem behaviours (Hooker, Bowman & Padgett Coehlo et al., 2002). At follow up, both the mental and physical health of carers were significantly associated with the amount of increase in patients' problematic behaviours.

### **3.2.6 Assessing Impairment and Disability**

The social model of disability and impairment has important implications for the operationalisation of care recipient outcomes in research and clinical practice. Bowling (1991), for example, points out that the attempts to assess functional disability are inevitably compounded by conceptual difficulties and interactive factors. She argues that different patients may react differently to apparently similar levels of physical impairment, depending on their individual perception and their available material resources and social support (from their carer and beyond). Bowling also highlights that, despite the interactive nature of disability, "most measures narrowly focus on a range of mobility, domestic and self-care tasks, often, however, ignoring financial, emotional and social needs which may be equally or more important".

Table 3.2 examines some widely used measures of impairment. Among the six measures included, four make no specific reference to psychological impairment. This is surprising given the salience of psychological impairment in the profile of many chronically disabling conditions (especially in the elderly population) as well as the exacerbating effect mental impairment may have on many of the factors that are included in the instruments (e.g. – ability to self care). Furthermore, given the evidence discussed above suggesting the salience of mental impairment in the carer – care recipient relationship, such measures may be said to be of limited value in this area of work.

**Table 3.2: Instruments assessing impairment**

Scale	Factors	Reliability / Validity	Comments
Health Assessment Questionnaire (Fries et al., 1980)	- dressing & grooming, - rising, - eating, - walking, - hygiene, - reach, - grip, -outside activity, - sexual activity	Highly correlated with other measures (e.g. Functional Limitation profile). High test-retest reliability (0.98). Responses similar for self completion and professional administration.	Mainly used with rheumatoid arthritis patient groups. No specific reference to cognitive / mental impairment.
Index of Activities of Daily Living (Katz et al. 1963)	One overall disability score (contributed to by items on bathing, dressing, transferring, toileting, continence and feeding).	Little evidence of validity (Bowling, 1991). Internal reliability 0.74 to 0.88.	Very widely used and well established measure. No specific reference to cognitive / mental impairment. Underestimates dysfunction in community populations (Spector et al, 1987).
Townsend's Disability Scale (Townsend, 1979)	One overall disability score (contributed to by items on drinking, eating, evacuating, exercising, sleeping, hearing, washing, dressing, cooking, cleaning).	Little evidence of reliability or validity for original scale. Adaptations produced alpha of 0.70 to 0.75.	No specific reference to cognitive / mental impairment. Some items not very suitable for elderly samples.



The Barthel Index (Mahoney & Barthel, 1965)	One overall disability score (contributed to by items on feeding, mobility, toileting, bathing, washing, walking, stair use, dressing and incontinence).	Good predictive validity in relation to mortality, length of hospital stay and physician ratings of progress. Test retest reliability = 0.89.	No specific reference to cognitive / mental impairment. Change can occur beyond that measured by the end points of the scale (e.g.- a deterioration in very poor functioning may not captured).
Crichton Royal Behaviour Rating Scale (Robinson, 1968).	One overall disability score (contributed to by items on dressing, feeding, memory, orientation and confusion). A subscale can be derived for confusion. Later factor analysis identified two factors: capacity for self care and ability to walk).	Confusion subscale correlates well with clinical assessments for dementia. Wilkin & Thompson (1989) highlight that the scale lacks sensitivity to change.	Directly addresses cognitive / mental impairment. Home care activities excluded as scale was designed for institutionalised samples.
Clifton Assessment Procedures for the Elderly - Behavioural Rating Scale (Pattie & Gilleard, 1979).	Four subscales (physical disability, apathy, communication and social dependency) and one overall disability score.	Can discriminate between those requiring different degrees of help and with different levels of social adjustment. H Test-retest reliability (6 months) range from 0.69 to 0.84).	Directly addresses cognitive / mental impairment as well as physical impairment and behavioural dependency. Most extensively used scale of dependency in the UK.

### 3.2.7 The Effect of Respite Intervention on Care Recipient Condition

The extent to which supportive services adopt a 'dual focus', and consider the needs of both carer and care recipient, was discussed in chapter 2. It was concluded that in any carer support service evaluation an analysis is required of not just the effects on carers, but also the effects on the person who is being cared for (Pickard, 2004).

The effect of in-patient respite care provided outside of the familiar home environment might have particular potential for exerting an impact on the care recipients' condition. Especially for individuals with dementia, spatial disorientation and severe agitation can occur when faced with new surroundings

(McGilton et al. 2003). Despite this, however, the inclusion of care recipient outcomes in evaluations of respite programmes has been far from consistent. This may be seen as an oversight in both ethical and methodological terms.

In ethical terms, assessment of care recipient outcomes better addresses the balance between the rights of both members of the relationship. Indeed, the exclusion of care recipient outcomes would be against the basic proviso stated in the *National Strategy for Carers* (DH, 1999) that carer support services must never result in “taking away any of the rights of the people who need care, nor recognising their needs any the less. “

In methodological terms, the exclusion of care recipient outcomes in service evaluation is an oversight because it fails to recognise the fact that the well-being of one partner in the caring relationship will inevitably effect the well-being of the other. Evidence has already been discussed suggesting that deteriorations in the condition of care recipient may exacerbate the consequences of a caring role in terms of psychological well-being. In relation to respite care, this would imply that, if the intervention negatively effects the physical or emotional well-being of the care-recipient, then this is likely to impact what the carer is required to cope with on the return of the care recipient into their care (Zarit & Leitsch, 2001), thus negating the benefits they derive from the service.

A review of the respite care literature revealed six studies that examined the effects of residential respite intervention on care recipients (see table 3.3). Overall, the findings were positive and indicate that respite care does not inevitably have a negative impact on care recipient condition. While two studies showed no overall change, one study found an overall improvement in condition.

Notably, one other study reported an improvement in condition during respite which then declined back to baseline levels after the care recipient's return home (Neville & Byrne 2006).

**Table 3.3: Effects of respite on care recipients**

<b>Paper</b>	<b>Sample</b>	<b>Respite Form</b>	<b>Findings</b>
Burdz et al (1988)	N=55 Mixed Diagnoses	Residential Respite (2 weeks)	- No change in behaviour problems - No change in memory problems
Seltzer et al (1988)	N=37 100% Dementia	Residential Respite (2 weeks)	- Improvement in functional status for those with poor status at baseline - Decline in functional status for those with high status at baseline
Adler et al (1993)	N=37 100% Dementia	Residential Respite (2 weeks)	- No change in behaviour problems - No change in functional status (ADL)
Hirsch et al. (1993)	N=39 100% Dementia	Residential Respite (varied duration)	- 2 days post respite: Decline in behaviour and self-care - 14 days post respite: Behaviour and self-care returned to pre-respite levels
Homer & Gilleard (1994)	N=58 Mixed Diagnoses	Residential Respite (varied duration)	- Improvement in functional status
Neville & Byrne (2006)	N=100 29% Dementia	Residential Respite (varied duration)	- During respite: improvement in behaviour problems - After respite: behaviour problems increased again to baseline levels

The only overall decline in condition was reported immediately (2 days) after intervention in patients' behaviour and self care (Hirsch et al., 1993). However, the authors went on to report that levels of behaviour and self-care had returned to

normal after 14 days. One other study reported that the change in care recipient condition exhibited after respite was moderated by the care recipient condition at baseline. Seltzer et al (1988) found that that patients with poorest status tended to show improvement on some measures following respite, while patients with higher initial levels of performance tended to show slight worsening following respite.

## **4. Subjective Burden**

### **4.1 Carer Burden and the Cognitive Revolution**

If human beings were simply passive responders to external stimuli then there would be no need to add to the section on objective burden. Carer burden would be entirely a function of the level of dependency of the care recipient. However, as Bandura (1999) points out "the self system is not merely a conduit for external influences as structural and biological reductionists might claim. People are both producers as well as products of their life conditions."

In line with the 'cognitive revolution' within the social and medical sciences, the concept of carer burden has become increasingly refined to accommodate the fact that two carers, faced with exactly the same level of objective burden, may respond differently in terms of psychological and physical outcomes. The subjective impact of a caring role has been increasingly incorporated into research in this area. Indeed, recent definitions of the concept by some authors seem to have come full circle and focus entirely on subjective responses with objective aspects relegated to the role of antecedents. An example is that of Sherwood et al (2005) who define caregiver burden as "an emotional reaction to

the demands of the care situation, dictated in large part by the care recipient's functional and mental status."

## **4.2 Subjective Burden and Depression**

Although subjective caregiver burden and depressive symptoms are both rooted in the caregiver's emotional and psychological reaction to care demands, the relationship between the two is unclear. In particular, there is a question over whether subjective carer burden differs conceptually from other, more generic concepts of psychological well-being such as depression.

Some previous studies have suggested that caregiver burden and depressive symptoms are interrelated, with burden being an antecedent to depressive symptoms (Clyburn et al 2000). In their more recent analysis, however, Sherwood et al (2005) found that caregiver burden only came near significance as a predictor of depressive symptoms, and that caregiver depressive symptoms did not predict burden.

It may be, therefore, that just because a caring role is perceived as presenting a high level of burden by the carer, this does not mean that this burden will translate into poor psychological well-being. Rather, for a high level of burden to translate into poor well-being it may have to be perceived as also having other, adverse characteristics.

A parallel can be drawn here from the study of occupational stress. Robert Karasek (1979) originally developed and provided evidence for the "job strain" concept and model, arguing that for work to have an adverse effects on well-being

it must not only be perceived as demanding, but as unfulfilling and out of the worker's control. Karasek saw job strain as resulting "not from a single aspect of the work environment, but from the joint effects of the demands of a work situation and the range of decision-making freedom (discretion) available to the worker facing those demands... Job strain occurs when job demands are high and job decision latitude is low". Therefore, it may be that the extent to which a high level of perceived burden results in depressive symptoms will, to some degree, depend upon how else it is appraised by the carer.

#### **4.3 The importance of appraisal**

An assessment of the burden intrinsic to one's caring role may to some degree depend upon assessment of what is problematic, unreasonable or beyond one's resources. With this in mind, and in line with the transactional paradigm of stress and coping pioneered by Lazarus & Folkman (1984), many writers have called for the inclusion of the appraisal processes into the concept of carer burden. Accordingly, definitions of carer burden have been refined by many writers to include the caregiver's judgment concerning the distress or difficulty associated with performing the caring role (Poulshock & Deimling, 1989).

Appraisal may be particularly relevant in relation to aspects of carer burden that relate to the behaviour of the care recipient. Evidence has already been discussed that points to behavioural, rather than physical aspects of a care recipient's condition as having the most impact on carers' well being. This behaviour, is of course always open to interpretation as it involves assumptions about the motivations of the care recipient. For example, a behaviour (such as constant demands for attention) may be reported as manipulative by one carer while another carer may well report this as simply evidence of dependency. The

extent to which measures of carer burden tap into such appraisals and interpretations is discussed in the next section.

#### **4.4 Assessing Carer Burden**

As the study of carer burden has expanded, so has the range of instruments designed to assess it. A review of the instruments available reveals a daunting range of options that vary widely in conceptual focus (as well as conceptual clarity) (see table 3.4).

Early measures tended to adopt a simplified, one-dimensional approach to carer burden. Within this group are instruments that tap a global dimension of burden (eg - Zarit Burden Interview; Zarit et al., 1980) as well as scales that remain focused on one, clearly defined dimension to the exclusion of other dimensions (eg – Caregiver Strain Index; Robinson, 1983).

The conceptual simplicity of such scales may have contributed to the fact that they are very widely used. However, uni-dimensional scales may fail to tap into (in the case of the Caregiver Strain Index), or tease out (in the case of the Zarit Burden Interview), the interactions between different aspects of the caring role, and may require supplementation with other measures. The majority of instruments that have been developed since the original uni-dimensional scales have attempted to untangle the various dimensions of carer burden and allow analysis of their interrelationships. These range from instruments that adopt a dichotomous approach to the concept (eg – Vitaliano et al, 1989) to scales that contain several distinct subscales (eg - Carers' Assessment of Difficulties Index: Nolan & Grant, 1992).

While numerous subscales have the advantage of providing a precise conceptual approach to carer burden, the inclusion of six or seven subscales can become cumbersome in terms of research design and analysis, as well as lead to difficulties in establishing independence between the dimensions (eg - Cost of Care Index: Kosberg & Cairl, 1986).

While many of the instruments include both objective and subjective elements, few manage to draw out distinctions between the traditional stimulus response concepts of objective burden and subjective reaction and carers' appraisals of burden. In particular, most measures do not address (as a separate dimension) appraisals by the carer of the care recipient's behaviour. One exception is the Montgomery-Borgatta Caregiver Burden Scale (Montgomery et al., 1985) that includes a dimension labelled *subjective demand* that examines perceptions of the carer regarding attempts by the dependent relative in manipulating the caregiver; unreasonable requests of the caregiver; feeling by the caregiver of being taken advantage of by the dependent relative; and demands made by the dependent relative that are over and above what is needed.



**Table 3.4: Instruments assessing carer burden**

	Scale	Subscales	Comments	Reliability
1	Zarit Burden Interview (Zarit <i>et al.</i> 1980)	- Global Burden (.92)	Very widely used. Standardised on caregivers of dementia patients.	Internal: $\alpha = .92$ Test-Retest: .71
2	Caregiver Strain Index Robinson (1983)	- Objective Burden (.86)	Very widely used. Objective burden covers employment, financial, physical, social and time. Standardised on caregivers of recently hospitalized older adults.	Internal: $\alpha = .86$ Test-Retest: (not available)
3	Montgomery-Borgatta Caregiver Burden Scale (Montgomery <i>et al.</i> , 1985)	- Objective Burden (OB) - Subjective Demand (SD) - Subjective Stress (SS)	Standardised on several samples of caregivers who have participated in a wide range of studies.	Internal: $\alpha = .90$ (OB), .82 (SD), .88 (SS) Test-Retest: (not available) Normative data ranges (mean, std): OB = 19.3 (3.8) to 19.5 (3.2) SD = 12.6 (2.4) to 12.7 (2.0) SS = 13.2 (3.3) to 13.6 (2.9).
4	Cost of Care Index Kosberg & Cairl (1986)	- Personal and social restrictions - Physical and emotional problems - Economic costs - Value investment in caregiving - Perception of the care- receiver as provocateur (total alpha .91)	All negative items. Standardised on sample of Alzheimer caregivers.	Internal: $\alpha = .91$ Test-Retest:  The high intercorrelations among four of their five subscales raise the question of independence of these scales.
5	Multidimensional Caregiver Burden Inventory (Novak & Guest, 1989)	- Time - Behaviour - Physical - Social - Emotional	Standardised on sample of Alzheimer caregivers. Lengthy - 15 to 20 minutes to administer	Internal: $\alpha = .73$ to .86 Test-Retest: not available

6	Caregiver Hassles Scale (Kinney & Stephens, 1989)	<ul style="list-style-type: none"> <li>- Assistance in basic ADL</li> <li>- Assistance in IADL</li> <li>- Care-recipient's cognitive status</li> <li>- Care-recipient's behaviour</li> <li>- Caregiver's social network</li> </ul>	Standardised on sample of Alzheimer caregivers. Very lengthy.	Internal: $\alpha = .91$ Test-Retest:
7	Screen for Caregiver Burden (Vitaliano et al., 1991)	<ul style="list-style-type: none"> <li>- Objective Burden</li> <li>- Subjective Burden</li> </ul>	Some inclusion of subjective statements in the objective burden score.	Internal: $\alpha = .85$ (OB) and $.88$ (SB) Test-Retest: $.64$ (OB) and $.70$ (SB)
8	Caregiver Burden Measures (Siegel et al. 1991)	<ul style="list-style-type: none"> <li>- Employment</li> <li>- Financial</li> <li>- Physical</li> <li>- Social</li> <li>- Time</li> </ul>	Standardised on sample of cancer patients and their informal caregivers.	None available
9	Caregiver Reaction Assessment (Given et al., 1992)	<ul style="list-style-type: none"> <li>- Self-esteem</li> <li>- Family support</li> <li>- Finances</li> <li>- Impact on schedule</li> <li>- Impact on health</li> </ul>	Standardised on sample of cancer patients and their informal caregivers.	Internal: $\alpha = .62$ to $.83$
10	Carers' Assessment of Difficulties Index (Nolan & Grant, 1992)	<ul style="list-style-type: none"> <li>- Carer-dependant relationships</li> <li>- Reactions to caregiving</li> <li>- Physical demands of caring</li> <li>- Restricted social life</li> <li>- Poor family support</li> <li>- Poor professional support</li> <li>- Financial consequences</li> </ul>		Internal: $\alpha = .71$ to $.84$
11	Caregiving Burden Scale (Gerritsen & Van der Ende, 1994)	<ul style="list-style-type: none"> <li>- Subjective burden: relationship</li> <li>- Subjective burden: personal</li> </ul>	Standardised on carers for people with dementia.	Internal: $\alpha = .77$ for both scales



## **Chapter 4: Social Functioning & Support**

### **1. Social Support and Well-Being**

#### **1.1 Social Support and Stress**

#### **1.2 Social Support and Behaviour**

### **3. Conceptualising social functioning and support**

#### **2.1 Structural concepts of social support**

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#### **2.3 Sources and Functions of Social Support**

### **3. Social support among caregivers**

#### **3.2 Sources of support to carers**

#### **3.2 Functions of support to carers**

## **1. Social Support and Well-Being**

An interest in how our social relationships may affect our health and well-being dates back at least as far as Durkheim's (1951) work on suicide, which has been cited as evidence that modern life disrupts social cohesion and results in a greater risk of morbidity and mortality—including self-destructive behaviours and suicide. Since then, our social networks (Brissette et al, 2000), the support we receive from others (Cohen et al., 2000), and the quality that we attribute to our social interactions (Kiecolt-Glaser & Newton, 2001) have all been identified as contributing to health and wellbeing.

There are a number of ways in which our social relationships may be relevant to our health, and various theories have arisen over the years to explain the link (Cohen, 1988). These theories are by no means mutually exclusive, and indeed, it may be that the only plausible conclusion is that social relationships affect our health in all the ways described.

### **1.1 Social Support and Stress**

At maybe the most fundamental level of analysis, social support is thought to affect our health via an effect on physiological functioning. In an extensive review of the literature, Uchino (2006) found that social support was consistently related to effects on aspects of cardiovascular, immune and endocrine functioning. There are a number of ways in which this may occur, but at the heart of many explanations lies the concept of stress, and the extent to which the presence (or at least the perception) of support may 'buffer' physiological reactions to stressful stimuli.

This 'stress buffer' hypothesis of social support was pioneered by Cohen & Wills (1985). The theory suggests that social support benefits well-being by providing

the psychological and practical resources needed to cope with stress. The model predicts that social support is beneficial for those encountering stressful demands but does not play a role (or plays a minimal role) in protecting the well-being of those not under highly stressful demands. In other words, the stress buffer hypothesis is an 'interactive' model that suggests a moderating or mediating role for stress in the link between social support and health. There has been substantial evidence for a stress buffering effect of social support, both in relation to mental health outcomes, and concerning the attenuation of acute physiological reactions to stress (Lepore et al., 1993).

## **1.2 Social Support and Behaviour**

It has also been argued that social support may not exclusively depend on stress for its health protective effects, but rather, influences well-being in all circumstances. This 'main effect' theory (a label maybe intended to contrast it with the interaction predicted by the stress buffer hypothesis) would predict an effect of social support in all circumstances, not just those characterised by a high level of demand. One way in which social support and relationships may operate in this way is by their influence over behaviour, and in particular, over health related behaviour (such as smoking, drinking and sexual behaviour) (Stephoe et al., 1996). Having a wide range of network ties may provide sources of information, help or just opinion that could influence health behaviours, resulting in better access or use of healthcare services, or simply helping one to avoid high-risk situations. In fact, several theories of health related behaviour have included social factors within their explanatory model (such as the inclusion of social norms as a factor in the theory of Planned Behaviour (Ajzen, 1988)).

## **2. Conceptualising social functioning and support**

It would not be true to say that findings relating to social support and health have been consistent, however, since many studies have revealed a lack of, or even reversals in, the expected positive relationship between support and health (Schwarzer & Leppin, 1991; Shumaker & Hill, 1991).

This inconsistency can be seen as largely due to the complexity of social support and the inconsistency in which it is both conceptualised and operationalised. For example, one salient conceptual distinction in the area is that between objective, structural definitions and the more subjective, cognitive approaches.

### **2.1 Structural concepts of social support**

Structural conceptualisations of social support emerged out of social network analysis. A pioneer of this work was Tolsdorf (1976), who identified the main social support concepts to include the *size* of the network, assessed in terms of the number of people listed by the individual as being part of their social network (i.e. according to the criteria of knowing each other by name and having some contact at least once a year) and *adjacency density*, that is, an approximation of the extent to which the respondent's network is interconnected.

Another, structural approach to examining social functioning is to focus on the extent or frequency of social activity. Again, this is a largely non-evaluative approach as social activity can have both positive and negative meanings for the individual concerned (eg – interaction with friends may occasionally result in conflict rather than support).

Despite the non-evaluative nature of the structural approach, it has produced an abundance of compelling evidence for a causal link between structural aspects social support and health. As mentioned at the beginning of this chapter, the earliest, and maybe best-known example of this came from the work of Emile Durkheim (1951) on suicide. His work provided evidence to suggest that suicide varies inversely with the degree of social integration. Durkheim asserted that people who are well integrated into a group are cushioned to a significant extent from the impact of frustrations and stressors that face them in their lives. As a result, they are less likely to experience poor psychological well being and to resort to extreme self destructive behaviour such as suicide.

Later, Berkman & Syme (1979) also adopted a structural approach to social support in that they assessed the presence and extent of four types of social ties (marriage, family, church-related, and other group affiliations). The findings revealed that these ties predicted mortality 9 years later (independently of other baseline factors).

## **2.2 Subjective concepts of social support**

The study of social support, like many other areas of the health and social sciences, has undergone a cognitive revolution. That is, it has become driven in recent years by the view that individuals act as information processors rather than passive responders.

In relation to stress, importance has increasingly been placed on how individuals appraise their environment (including their social environment), and how those appraisals act as mediators between potentially stressful stimuli and its effects on well-being (Folkman & Lazarus, 1984).



The emphasis on individual interpretation and bias has gone as far as to result in social support being conceptualised in a way that resembles a personality variable. Perceived social support is seen as representing a trait-like sense of acceptance that develops as the result of early attachment experiences (Sarason et al., 1990).

The concept of perceived support, like structural aspects of social support, has been linked empirically with positive health and well-being. In fact, taken as a whole, the evidence seems to suggest that it is this conceptualization of support that has been found to be most closely related to health and well-being. For example, studies have suggested that perceptions of support may moderate (or buffer) the relationship between stress and psychological outcomes, whereas structural measures of received support do not (Dunkel-Schetter & Bennett, 1990).

However, one criticism of this perception focused view of social support is that the close relationship with health and well-being is simply due to the fact that they are confounded outcomes, and essentially the same construct. Just as the self-report of physical symptoms has been argued to reflect more about psychological state than physical state (Stansfeld et al. 1993), so may the reporting of unsatisfactory social support. Indeed, it was Sarason et al., (1990), who were major pioneers of the perceived social support concept, that described it as involving working models of the self and the development of cognitive schema rather akin to Aaron T. Beck's (1964) theory of depression.

### **2.3 Sources and Functions of Social Support**

In response to the wide-ranging nature of the social support concept, and in an effort to more precisely pinpoint what may be beneficial to well-being within an individual's social environment, many writers have attempted to refine the concept and operationalise it in more precise terms.

An example of how a more specific approach to the study of social support and health can be valuable concerns the sources of support. In a review of the social support literature it was observed that the sources of support were rarely specified or analysed separately (Winemiller et al. 1993). This is likely to obscure many interesting patterns in the effects of support on health. For example, empirical evidence suggests that while satisfaction with support from a wide range of sources is associated with females' health, men's health is dependent almost entirely upon the perceived adequacy of spousal / partner support, with support from others failing to account for any additional variance (Richman et al, 1991).

Other writers have drawn attention to the various functional definitions of social support, and draw examples between, for example, emotional support and practical support. Weiss (1974) was one of the first writers to identify functions within social support. Weiss saw social support as incorporating various 'social provisions' that reflect what we receive from relationships with other people. The six provisions include guidance (advice or information), reliable alliance (assurance that others can be counted on in times of stress), reassurance of worth (recognition of one's competence), attachment (emotional closeness), social integration (a sense of belonging to a group of friends, akin to the structural concepts discussed earlier), and opportunity for nurturance (providing assistance to others). Examination of the functions of support in this way has enabled

researchers to predict adaptation to stress among a wide variety of populations, including post-partum women, the elderly, and individuals working in stressful job situations (eg – Cutrona et al. 1998; Schmitz et al. 1997).

### **3. Social support among caregivers**

The importance of social support to the well being of carers has been extensively documented. In particular, there are many examples of studies documenting the importance of support to caregivers' health and well-being (eg- Douglas & Spellacy, 2000; Chan, 2000).

Reflecting the literature as a whole, however, there is a shortage of research attempting to identify which forms of support are most effective in alleviating caregiver burden, or who the most effective sources of that support may be.

#### **3.1 Sources of support to carers**

Concerning the sources of support, there is evidence to suggest that caregivers benefit more from the quality of one particular relationship. One study examined 95 married daughters caring for parents with dementia (and 1,195 members of their social networks) to investigate factors differentiating individuals who were and were not a source of social support or interpersonal stress (ITS) to women (Suitor & Pillemer, 1993). Findings indicated that siblings and friends were almost equally important sources of support. Subsequent findings from the same research team suggested that the importance of support from different sources may actually be moderated by the type of support concerned (Suitor & Pillemer, 1996). Caregivers reported that friends were the most prominent source of

emotional support, while siblings were the greatest source of both instrumental support.

Another important finding regarding the relative importance of various types of support from this latter study concerned 'experiential similarity'. Supporters who had similar caregiving experiences were perceived as more empathetic and helpful (Suitor & Pillemer, 1996). This is understandable when we consider that a caring role often involves experiences and a level of demands outside that experienced in 'normal' life. Caregivers may often be of the view that relatives and friends with no caregiving experience themselves cannot understand what they are going through, and may perceive a lack of empathy from these members of their social network..

### **3.2 Functions of support to carers**

Regarding the functions of support, Thompson et al. (1993) examined the relationships between six different types of social support (including emotional support, practical help and social activity) and burden among caregivers of frail elders. The findings suggested that not all types of social support are equal, and that structurally defined levels of social contact and activity seem to be most crucial to carers' well being. Specifically, there was evidence that engaging in social interaction for fun and recreation (rather than perceptions of emotional support for example) appeared to be most important in diminishing the burden of caregiving.

In a more recent study, it was again the structural concepts of social integration and activity that seemed to be most crucial, this time in terms of predicting the

extent to which caregivers positively experienced supportive interventions. In a study of respite care, Nicoll et al. (2002) found satisfaction with respite care to be correlated significantly with the numbers of people in carers current social support network, albeit not with any of the other four forms of social support that were assessed.

It is likely that carers are very aware of the importance of social contact and activity to their well-being. For example, in a recent review of research into the expressed social support needs of family carers of the elderly the main need to emerge was that carers fear social isolation and wish to network in groups with peers (Stolz et al, 2004),.

This fear of social isolation, and the evident importance of social activity and integration to well-being, may reflect the fact that a constriction of social activities is one of the most frequently noted consequences of a caring role (Miller & Montgomery, 1990). In a recent survey by Carers UK, over three-quarters of carers reported that they gave up holidays, leisure pursuits, or family celebrations because of their caring responsibilities (Carers UK, 2001). Therefore, social activity and integration may be so important to carers simply because the prospect of social isolation is so real.

## **Chapter 5: The Effects of Respite on Carers:**

### **A Systematic Review of the Literature**

- 1. Introduction**
- 2. Methods**
- 3. Results Tables**
- 4. Discussion**
  - 4.1 Who has been the subject of respite care research?**
  - 4.2 Does respite lead to improvements in carers' well-being ?**
  - 4.3 Does respite delay institutionalisation of the care-recipient ?**
  - 4.4 What influences the effectiveness of respite intervention ?**
    - 4.4.1 Social factors**
    - 4.4.2 Type of respite**
    - 4.4.3 Care-recipient decline during respite**
    - 4.4.4 Type of carer**
    - 4.4.5 Recent versus older studies**
- 5. What methodological issues affect the results of respite evaluation?**
  - 5.1 Use of controls**
  - 5.2 Allocation to groups**
  - 5.3 Uncontrolled variability in the use of respite**
  - 5.4 Sample size**
  - 5.5 Sensitivity of outcome measures**
- 6. Conclusion**

## **1. Introduction**

The saliency of respite and the extensive resources invested in its provision make it important to establish the efficacy of respite care. This chapter sets out to systematically examine previous research on respite care in order to address the following questions: Who has been the subject of respite care research? Does respite lead to improvements in carers' well-being? Does respite delay the decision to institutionalise the care-recipient? Which factors may influence the effectiveness of respite intervention? And finally, what methodological issues may influence the results of respite evaluation?

Previous reviews have been conducted into the effects of carer support intervention (including respite care). Many of these reviews, however, have been limited to a very small number of studies (Knight, et al., 1993; Flint, 1995), included only particular forms of study or research design, such as controlled trials (Thompson & Briggs, 2000), or been confined to a particular population such as dementia carers or elderly carers (Arksey, et al., 2004; Sorensen et al., 2002).

The aim of this review was to address the diversity in carer support work and adopt as broad a scope as possible. In particular, an attempt was made to reflect the varying forms that respite can take, which include residential care, day care and in-home care. In addition this review sought to include quasi-experimental and observational studies as well as draw from a wider pool of research that reflects the full range of ages and types of carers that respite is aimed at.

In designing the review, and in particular, the information to be extracted from each article considered, it was important to consider the theoretical background to respite care and its aims.

It is notable that respite care intervention is, to some degree, a theoretical. For example, a recent review of caregiver interventions actually omitted respite care studies because they are “Not linked to psychologically based theories that would help explain why these results are occurring” (Gallagher-Thompson & Coon, 2007).

Despite this, earlier chapters have already suggested a theoretical basis to how respite care intervention can be evaluated. This is informed by a Stress Process Model (Pearlin et al 1990) - which is often applied to caregivers. In regard to stressors, Pearlin et al. define two types of - *Primary* stressors are linked directly to the individual and the disability, while the *secondary* stressors arise from the demands of the caregiving role itself (eg – represented in this study by the dependency variable). Third variables, such as social supports, may moderate or mediate how people are impacted differently by the same stressors, and may help to sustain the caregiver and lessen the effect of the stressors. In relation to outcome, Pearlin et al. suggest that stress among carers may manifest itself in their physical and mental health, as well as their ability to sustain their own social roles.

In total, Pearlin et al. distinguish four domains for evaluation:

- 1) background and contextual factors (age, sex)
- 2) stressors (care recipient dependency)
- 3) mediators / moderators of stress (social activity)
- 4) outcomes (depression, physical symptoms, physiological functioning)

The present literature review set out to examine the literature on respite and the extent to which these variables are examined and / or relevant within the context of respite care intervention.



## 2. Methods

Literature searches were performed using several computerised databases.

Table 6.1 lists the databases included in the search and the years included.

**Table 5.1: Databases and years covered by literature search**

Database	Years
Medline	1966 – 2006
PsycINFO	1887 – 2006
Cumulative Index to Nursing and Allied Health	1982 – 2006
BIDS International Bibliography of the Social Sciences	1951 – 2006
BIDS IGENTA Journals Database	1988 – 2006

Articles were selected for review if they reported work assessing *the effects of respite intervention on informal carers*. Articles simply describing a respite programme, reporting on who uses respite programmes, or confining analysis to the effect of respite on the care-recipient were excluded. The search was also confined to English language research reports.

The search term '*carer\* OR caregiv\*\**' was used in order to retrieve articles containing the words 'carer', 'carers', 'caregiver', 'caregivers' and 'caregiving'. In searches of each of the five databases, this term was combined (using the *AND* operator) with the terms '*respite*', '*short break*' and '*holiday*'. Thus, fifteen individual searches were run. The reference sections of retrieved publications and the contents of Dissertation Abstracts International were also included in the search for additional research relevant to the review.

### **3. Results Tables**

The search yielded 55 studies that met the criteria, the majority of which were reported in peer review journals. The first column of Table 5.2 provides an index of the authors and year of publication. This table also sets out sample characteristics, care-recipient characteristics, the nature of the intervention and the method of allocation to groups. The quality of information in each paper was variable. Consequently, in some cases, important information such as the age of the sample or the precise amount of respite provided was not available.

In the most recent and largest of the previous reviews of respite research, Arksey et al (2004) concluded that a meta-analysis was not appropriate since the studies were too heterogeneous to be sensibly combined. This conclusion is equally applicable to the present review, which also revealed a great diversity in study design, type of intervention, setting of intervention, and a variety of outcome measures. Therefore, rather than carry out a quantitative synthesis of the data that may prove misleading, an attempt was made to assess the overall results and potential heterogeneity of findings using a qualitative approach.

Table 5.2 sets out the independent variables examined in each study, as well as the dependent variables used to assess the impact of respite on carers. In each case, outcomes due to respite are classified as representing improvement, deterioration or no change in carers' well-being.

Table 5.2: Papers under review

	PAPER <sup>a</sup>	Subject Characteristics (experimental / control) <sup>b</sup>	Care recipient	Intervention and duration	Allocation of groups (if applicable)
Residential Respite					
1	(Subramanian 1985)	n = 36 mean age = 29 co-resident = 100%	Children of Carers	Residential <i>Overnight respite of various duration and frequency.</i>  With counseling.	
2	(Scharlach & Frenzel, 1986)	n = 99 Mean age = 72 100% female	Relatives of Carers  Elderly (physical & mental disabilities)	Residential <i>Various duration and frequency</i>	
3	(Burdz et al. 1988)	n = 35 / 20 mean age = 57 / 62 female = 89% / 75%	Relatives of Carers  Elderly (dementia and non- dementia groups)	Residential <i>One episode of 2 weeks</i>	Quasi experimental (waiting list control)
4	(Botuck and Winsberg 1991)	n = 14 female = 100% in paid employment = 50% co-resident = 100%	Children of Carers  Cerebral Palsy	Residential <i>overnight respite involving 10 overnight stays</i>	
5	(Adler et al 1993)	n = 37 female = 92% mean age = 64 in paid employment = 16%	Relatives of Carers  Dementia	Residential <i>One episode of 2 weeks</i>	

	PAPER*	Subject Characteristics (experimental / control) <sup>b</sup>	Care recipient	Intervention and duration	Allocation of groups (if applicable)
6	(Burcz 1993) (D)	n=32	Relatives of Carers Elderly 17 non-dementia 16 dementia	Residential	
7	(Larkin and Hopcroft 1993)	n = 23 female = 96% mean age = 64 in paid employment = 22% co resident = 50%	Relatives of Carers Alzheimer's Disease	Residential <i>One episode of 2 weeks</i>	
8	(Skelly et al 1993)	n = 16 / 14 female = 'most' mean age = 67 co resident = 'most'	Relatives of Carers -lively	Residential One episode	Quasi experimental
9	(Chi and Wong 1994)	n = 40 female = 21% in paid employment = 45% co resident = 74%	Relatives of Carers -lively	Residential One episode	
10	(Homer and Gilleard 1994)	n = 54 female = 52% mean age = 66	Relatives of Carers -lively	Residential One episode	
11	(Carasco - Davies and Harvey 1995)	n = 39 female = 72%	Relatives of Carers Stroke or VS	Residential One episode	

	PAPER*	Subject Characteristics (experimental / control)*	Care recipient	Intervention and duration	Allocation of groups (if applicable)
12	(Mausner 1995)	n = 8 families	Children of Carers Various conditions	Residential respite provided by other families	
13	(Martin 2001) (D)	n = 50/24	Children of Carers Developmental disabilities	Residential	Quasi experimental
14	(Treloar et al., 2001)	n = no info	Relatives of Carers Elderly	Residential (8 pm to 8 am)	
Day Care					
15	(Gillcord, 1987)	N = 129	Relatives of Carers Elderly	Day Care Six months of attendance	
16	(Johnson and Maguire 1999)	N = 48 female = 50% mean age = 75	Relatives of Carers Geriatric and psychogeriatric patients	Day Care 4 months at 1 - 3 times per week	
17	(Biegel et al., 1993)	n = 171 Mean age = 58 yrs Female = 70%	Relatives of Carers Alzheimer's Disease	Day Care	Quasi experimental (based on existing service use)
18	(Hartens, 1995) (D)		Spouse of Carer Dementia	Day care	Quasi experimental

	PAPER*	Subject Characteristics (experimental / control)*	Care recipient	Intervention and duration	Allocation of groups (if applicable)
19	(Stephenson et al 1995)	n = 92	Relatives or Carers Elderly	Day care	
20	(Lorenzini and Bates 1997)	n = 45 / 45	Relatives or Carers Dementia	Day care	Quasi experimental
21	(Zarit et al 1998)	n = 72 / 120 Mean age = 69 Female = 77%	Relatives or Carers Dementia	Day Care 2 times a week	Quasi experimental (control group lives in area with day care unavailable)
22	(Jenett et al 1999)	n = 175 Mean age = 68 yrs 82% female	Relatives or Carers Dementia	Day Care 3 and 12 months of use	
23	(Dziogielewski & Ricks 2000)	n = 26 Mean age = 82 85% female	Relatives or Carers Dementia	Day Care	
24	(Ludsch et al 2001)	n=250	Relatives or Carers Dementia	Day Care 2 days a week for 3 months	
25	(Gaugler et al 2002)	n= 188 / 221 Mean age = 69 Female = 81%	Relatives or Carers Dementia	Day care 3 month period	Quasi experimental

	PAPER*	Subject Characteristics (experimental / control) <sup>b</sup>	Care recipient	Intervention and duration	Allocation of groups (if applicable)
In-Home Respite					
26	(Cimcorvole and Lewis 1987)	n = 31	Relatives of Carers Alzheimer's Disease	n = none up to 6 months at 4-6 hours per week	
27	(Marks 1993)	n = 20/20 Mean age = 60 female = 95%	Relatives of Carers -elderly	n = none 4 to 6 hrs per week for With intervention for patient (eg. socialization)	Quasi-experimental (waiting list control)
28	(Davieson 1985) (D)	n = 95	Relatives of Carers Elderly	n = none	
29	(Nickbuhl 1985) (D)	n = 47	Relatives of Carers Elderly	n = none 2-4 hrs wk for 3 months	Quasi-experimental (controls lived in area with no respite available)
30	(Rimrennan 1985)	n = 28/25 female = 100% mean age = 28 co resident = 100%	Children of Carers Mentally retarded and / or emotionally disturbed	n = none for 18 months at 6 hours per week	Quasi-experimental (waiting list control)
31	(Breslin 1980) (D)	n = 65/21 female = 100%	Children of carer Developmental disabilities	n = none	Quasi-experimental (waiting list control)

	PAPER <sup>a</sup>	Subject Characteristics (experimental / control) <sup>b</sup>	Care recipient	Intervention and duration	Allocation of groups (if applicable)
32	(Hughes et al 1990)	n = 119 / 114	Relatives of Carers  Disabled (ie. 2+ ADL impairments)	n = home for 6 months  With social work / nursing	Random
33	(Vohles et al 1990)	n = 22 / 20 (co-resident) = 100%	Relatives of Carers  Dementia	n = home 6 months at 4 hrs per week  With support visits / support group / education	Random
34	(Okuy and Volland 1990)	n = 92 / 92 female = 78% / 82% mean age = 52	Relatives of Carers  Elderly	n = home  With support group / nursing / education	Quasi experimental
35	(Sherman 1995)	n = 20 families (co-resident) = 100%	Children of Carers  Chronic illness	n = home	
36	(Shu et al 2002)	n = 49 Mean age = 41 years Female = 61%	Children of Carers  Intellectual disability	n = home  With carer interventions re seeking support and coping	
37	(Grant et al 2003)	n = 60 Mean age = 73 years Female = 82%	Spouse of Carer  Dementia	n = home 10 days x 6 hrs per day	Random
38	(Pore et al 2005)	n = 100 Mean age = 80 Female = 81%	Relative of Carer  Dementia	n = home varying duration	



	PAPER*	Subject Characteristics (experimental / control) <sup>b</sup>	Care recipient	Intervention and duration	Allocation of groups (if applicable)
Mixed Interventions					
39	(Maysor 1988) (D)	n = 1512 Female = 100%	Relatives of Carers  -Isle of Wight	Voice	Quasi-experimental
40	(Lawton et al 1990)	n = 317 / 316 female = 91% / 92% mean age = 60 / 59 in paid employment = 33% / 35% co-resident = 88%	Relatives of Carers  Alzheimer's Disease	Voice choice given to carer available for 12 months  With education / counseling	Random
41	(Levin et al 1989)	n = 137	Relatives of Carers  Dementia	Voice available for 12 months	
42	(Montgomery and Borgatta 1989)	n = 54 / 48 groups female = 79% in paid employment = 40%	Relatives of Carers  Elderly	Voice choice given to carer available for 12 months  With education / support group	Random
43	(Rimmman et al 1989)	n = 78 female = 100% mean age = 48 in paid employment = 52% co-resident = 100%	Children of Carers  Mentally retarded and / or emotionally disturbed	Voice for 6 months	

	PAPER*	Subject Characteristics (experimental / control) <sup>b</sup>	Care recipient	Intervention and duration	Allocation of groups (if applicable)
44	(Berry et al 1991)	n = 40 female = 100% in paid employment = 30% co-resident = 100%	Relatives of Carers  Dementia	Video	
45	(Deirling 1991)	n = 78	Relatives of Carers  Alzheimer's disease	Video for 4 months	
46	(Corlin et al 1992)	n = 7 + 8 female = 100% + 75% mean age = 65 + 65 co-resident = 100%	Relatives of Carers  Alzheimer's Disease	Video for 16 months at 2 days a week	Quasi experimental (stratified allocation)
47	(Javed et al 1992)	n = 36	Children of Carers  Special needs	Video of various duration	
48	(Kosloski and Vongvanit 1992)	n = 45 / 25 female = 80% / 89%	Relatives of Carers  Alzheimer's Disease	Video of various duration and frequency	Quasi experimental (waiting list control)
49	(Heis et al 1994)	n = 130 originally 12 at 6 months and 12 at 12 months follow up female = 89% mean age = 65	Relatives of Carers  Chronically ill	Video 4 hours per week	
50	(Pinchill et al 1995)	n = 20 / 12 female = 75% mean age = 62	Relatives of Carers  Dementia	Video  With education, medication training and support group - tailored for each carer	Random

Table 2.2. Summary of studies of caregiver burden

	PAPER <sup>a</sup>	Subject Characteristics (experimental / control) <sup>b</sup>	Care recipient	Intervention and duration	Allocation of groups (if applicable)
51	(Moskosh and Vangelatos 1985)	n = 12 <sup>c</sup>	Relatives of Carers Disability (K-2-ADL impairments)	Vixed (choice given to enter)	
52	(Cox 1992)	n = 23 Mean age = 52 yrs 93% female	Relatives of Carers Alzheimer's Disease	Vixed 6 month period	
53	(Bruns & Burchard 2000)	n = 33 / 28	Children of Carers Emotional & behavioural disturbance	Vixed Mean of 23hrs per month over 6 month period	Quasi experimental (waiting list control)
54	(Chiu et al 2000)	n = 27 / 28	Relatives of Carers Alzheimer's Disease	Vixed 18 months of use  With case management, occupational therapy and physical therapies	Quasi experimental
55	(Cowan & Reed 2002)	n = 87 Mean age = 34 yrs 92% female	Children of Carers Developmental disabilities	Vixed  With information developmental stimulation	

<sup>a</sup> D = dissertation<sup>b</sup> In prospective studies, stated sample sizes indicate the number of participants providing final follow up data. Original baseline sample sizes may have been larger

Table 5.3: Variables under consideration and findings

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home <sup>a</sup>	Attitude to Caring	Other outcomes / Comments
Residential Respite									
1	(Subramanian 1985)	- Time (Initial contact / 1 week)	I (POMS)						
2	(Scharlach & Frenzel 1986)	- One group cross sectional survey							- No standardized instruments used 72% reported respite had improved health. 38% reported respite improved patient health
3	(Burdz et al. 1988)	- Time (before respite / 5 weeks later - after respite)  - Group (dementia / non-dementia)  - Group (treatment / control)	-	NC (burden)	-	-	-	-	- No significant interaction between treatment group and time. - There was main effect of dementia group (dementia carers exhibited higher burden than non- dementia carers)

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home "	Attitude to Caring	Other outcomes / Comments
4	(Botuck and Winsberg 1991)	Time (2-3 weeks prior / 1-2 weeks prior / 5-6th day during respite / 3-4 days after respite)	(Brachman) (Norwich Depressed Mood Scale)						improvements in well-being both during and (3-4 days) after respite Mothers spent more time caring for themselves and in social activity
5	(Adler et al 1992)	Time (2 weeks before / day of discharge / 2 weeks after discharge)  - Illness care for (AD / non-AD)	(Geriatric Depression Scale)	(Burden interview)					improvements evident at end of respite but had returned to initial level at follow up assessment - improvements significant only among non-AD carers
6	(Buroz 1993) (D)	- Time (1 wk pre respite / 1 wk after respite / 1 month after time 2)	NC (CES-D) (LS)			NC (F Q)			- No effect of respite on patient condition

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home "	Attitude to Caring	Other outcomes / Comments
7	Clarkin and Poproff (1993)	Time (3 days before / during / 14 days after) - Previous respite (yes / no) Support in caring Pt ADL impairment	(36)				0	0	improvements in well-being did not remain at follow-up - Respite increased receptivity to long-term placement - High level of satisfaction with respite - 29% admission within 2 weeks of respite (admission not associated with Pt condition or carer stress)
8	(Skelly et al 1993)	- Group (exp / con)		(Burden interview)					- Correlation between memory and behaviour problems only in non respite group No such correlation among subjects who used respite

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home *	Attitude to Caring	Other outcomes / Comments
9	(Chi and Wong 1994)	Time (before / 1 month)							- Less receptivity to long-term placement* - Improved attitudes to caring role - No tests of significance
10	(Homer and Gilleard 1994)	Time (before / during respite)	I (G-HQ depression)						- No effect of respite on G-HQ somatic complaints or G-HQ anxiety and insomnia variables Deterioration in G-HQ social dysfunction
11	(Caradoc - Davies and Harvey 1995)	- Time (week before respite / 1 week after discharge)	(G-HQ) (Zung depression)	(personal distress subscale of Greene Scale)	-	NC	-	-	- No overall change in stress, only in personal distress subscale
12	(Mausner 1995)	- Time (6 month period in previous year / 6 month period in programme)	-	-	-	-	-	-	- Less physician assistance required in year of programme

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home *	Attitude to Caring	Other outcomes / Comments
13	(Vann, 2001) (D)	Time (pre respite post respite)  - Group (exp/ctrl)	(stress)						-flexibility in scheduling has no effect on respite benefits
14	(Trickett et al. 2001)	- Time (entry - 4 weeks)  - Group (new attenders / regular attenders)	(G-O) (BD)	(RSC)					- improvements only in new attenders of 4 week period. Regular attenders showed no improvement
Day Care									
15	(Gilliland 1987)	Time (at entry 6 months)	(emotional distress)						
16	(Johnson and Vaquero 1989)	Time (on entry to programme 12 months / 4 months)		NC (carer stress scale)					
17	(Riechel et al. 1993)	Group (no service use / out of home service use / in home service use / both service use) NB respite only mentioned as a feature of out of services)		(care- related emotional strain)					Out of home service users reported less emotional strain than non-users and in home service users



	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			*I* = improvement; *D* = deterioration; *nc* = no change; *-* = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home *	Attitude to Caring	Other outcomes / Comments
18	(Marlens, 1995) (D)	Group (exp/cont)	NC			NC (initial satisfaction)			
19	(Stephenson et al 1995)	- One group cross-sectional survey	*	*	*	*	*	*	- High satisfaction with respite
20	Lorenzini and Bates (1997)	- Group (users / non- users of respite)							
21	(Zarit et al 1998)	- Time (at entry 3 months / 12 months) - Group (respite / control)	(CES-D) (30) NC (PANAS)	(overload) NC (anxiety) (worry)					- No change over time in patients' condition
22	(Janot et al 1999)	- Time (after 3 months and 12 months of respite)							- Satisfaction was high at 3 months and remained high at 12 months
23	(Odeigilewski & Ricks 2000)	- One group cross- sectional survey							- Carer satisfaction high
24	(Leisch et al (2001)	- Time (at entry 3 months) - Type of day-care (medical care / social care)		(anger role overload & worry)					- No differences in effects between the types of day care

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home *	Attitude to Caring	Other outcomes / Comments
25	(Gouldner et al 2002)	Time (pre respite 3 months)  - Group (increased / decreased memory problems)	NC (CES-D)	NC (Role Overload)					interaction: those who used adult day services and reported decreases in memory hours were more likely to report decreases in role overload
In-Home Respite									
26	(uncervold and Ewin 1997)	Time (before / several weekly and monthly assessments)  - Group (contrast of case studies)	NC (BD) (Perceived Stress Scale)	NC (Burden interview)		NC			
27	(Wicks 1988)	- Group (exposure)	I (PSS)	NC (OS)					
28	(Davieson 1989) (D)	- One group cross- sectional survey		NC					- Quantity of respite had no effect on burden
29	(Faulstich 1989) (D)	- Time (only 3 months)  - Group (exposure)	NC	NC		NC (Continuity)			

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home "	Attitude to Caring	Other outcomes / Comments
30	(Himmelfran 1989)	Time (baseline at entry / 6 months / 12 months / 18 months)  Group (exp / con)		(QRS)					-or many dimensions the stress scale reduction reached a peak at 12 months showing some increase again at 18 months
31	(Breslin 1990) (D)	Group		NC (parenting stress)	NC (self-rated health)	NC (marital satisfaction)			
32	(Nichols et al 1990)	Time (baseline (before discharge from hospital) / 1 month / 6 months)  - Group (exp / control)	NC (marital)						Satisfaction with health care improved
33	(Mchido et al 1990)	- Time (at entry / 3 months / at end 6 months)  - Group (exp / con)	NC (CES-D) (STA)	-	-	-	-	-	- Carer QOL increased, reported as clinically (but not statistically) significant by authors

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home "	Attitude to Caring	Other outcomes / Comments
34	(Okoye and Vollano 1990)	Time (baseline / 1 / 2 / 3 / 6 / 9 / 12 months)  - Group (exp / control)	NC (G-Q)		NC (symptom checklist)	NC			- experimental group did NOT receive more respite than controls Changes were not considered to inspire confidence
35	(Sherman 1995)	Time (at entry / 6 months)	(somatisation subscale of BS)						Association between amount of respite used and somatisation
36	(Shu et al. 2002)	Time (pre respite / 3 months / 6 months of use)	(Chinco G-Q)						
37	(Grant et al. 2003)	Time (pre respite / week / 1 month)  - Group (vulnerable vs non-vulnerable carers?)	NC (mean D / A and BS)						Plasma epinephrine declined significantly in the vulnerable caregivers who received respite

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychological Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home "	Attitude to Caring	Other outcomes / Comments
38	(Follet et al. 2005)	Time (onset and end of in home respite)	I (PANAS)						The ending of home care was associated with decreased depressive symptoms. Cause and effect?
Mixed Interventions									
29	(Kaiser 1999, n=1)	Group (exp/cont)		(burden interview)					-form and duration of respite had no impact on findings
40	(Lawton et al 1989)	Time (at entry / 12 months) - Group (exp / con)	NC (C-G) / Brachum)	NC (Scale by authors)	NC (self-rated health)			NC (Scale by authors)	Patients with a carer in respite group lived in community 22 days longer on average
41	(Levin et al. 1989)	Time (at entry / 12 months)	NC (Psychological health)						
42	(Montgomery and Borgotta 1989)	Time (entry / 12 months / 20 months) - Group (6 combinations)  Type of Carer (spouse / adult children)		(Scale by hrs. author)			I/D		Respite delayed placement among child carers but encouraged placement among spouse carers

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home *	Attitude to Caring	Other outcomes / Comments
43	(Rimmerman et al 1995)	-high/low respite usage- desire to use accessibility need satisfaction  Self-esteem (high/ low)  Child characteristics (high/low functioning)		(Q-RG-F (loss))					Utilisation of respite was associated with improvements only in interaction with self-esteem and functioning of child (ie. benefits only for mothers with high self-esteem and low functioning child)
44	(Berry et al 1991)	Type of day (respite/ non-respite)  - Type of respite (day care/ in-home)				NC			Respite time spent with friends/ relations very small - in-home respite reduced caregiving activity BUT day care actually increased time spent caring
45	(Deimling 1991)	Time (before/4-6 months)  - Pt Functioning (stable/conditioning condition)	/NC (CES-D)	/NC	/NC (self report)				No improvements overall but interaction with pt condition (significant improvements within carers of stable pt's but no change among conditioning pt. carers)

	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home *	Attitude to Caring	Other outcomes / Comments
46	(Conlin et al 1992)	Time (entry / 5 wks / 10 wks)  - Group (exp / con)	(FOV6 Lowillman sub-scale)	(personal distress)			NC		No improvements in OVERALL mood / stress, effects only on subscales
47	(Lawton et al 1992)	- None (one sample survey)	-	-	-	-	-	-	- High carer satisfaction with respite
48	(Kosloski and Vernengo 1993)	- Time (at entry / 6 months)  Group (exp / con)  Amount of respite used	(moral - scale by authors)	(scale by authors)	-	NC	-	-	- Respite had no effect on objective burden
49	(Thors et al 1994)	Time (entry / 6 months / 12 months)	NC (FOV6)						- High carer satisfaction with respite



	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home "	Attitude to Caring	Other outcomes / Comments
50	Hinchcliff et al (1995)	Time (baseline / post intervention / 16 weeks follow up)  Group (exp / con)  Group (immediate / delayed intervention)	(G-Q) (C-S-R)						improvement stable at 16 weeks follow up for immediate intervention No improvement with delayed intervention implemented among original control group)
51	Kosloski and Montgomery (1995)	Amount of respite used							Significant negative relationship between amount of respite used and probability of nursing home placement Many factors including P1 disability, amount of care, and P1 age controlled



	PAPER	INDEPENDENT VARIABLES	IMPACT ON CARERS						
			'I' = improvement; 'D' = deterioration; 'nc' = no change; '-' = not assessed						
			Psychologic al Well-Being	Carer Stress or Burden	Reported Physical Health	Social Support or Activity	Nursing Home *	Attitude to Caring	Other outcomes / Comments
52	(Cox 1998)	Time (entry 8 months)	NC (CES-D) (32)						Patients' ADL condition deteriorated but behavioural condition improved
53	(Brins & Burchard 2000)	Time (entry 8 months)  - Group (exp / con)  - Also regression between hours of respite and outcome		10-5 personal strain subscale)		NC 10-5 social strain subscale)			More respite related to lower expressed need for placement
54	(Chu et al 2000)	- Time (at entry 8 month 12 months)		(overall burden)					
55	(Cowan & Reed 2002)	- Time (pre and post respite)	(PS - depression)	(PS parenting stress)		(PS social isolation)			- Demandingness and hyperactivity of child decreased

- a) Nursing home placement is included in this table as it is likely to reflect the well being of the carer. Improved (+) indicates that placement was delayed by respite provision
- b) Although exp group did not receive more respite, and hence respite care was not evaluated, this study is included in the review for illustrative purposes
- c) Assumed to indicate an unfavourable outcome, although the lack of a control group makes conclusions tentative
- d) Improved (+) indicates decreased receptivity to long-term placement
- e) Defined as those carers with a severe mismatch between caregiving demand and help received in the preceding 6 months

Abbreviations: BD - Beck Depression Inventory; CES-D - Center for Epidemiological Studies Depression Scale; POMS - Profile of Mood States; QRS - Questionnaire on Resources and Stress; QRS-F - Coping Resources of Stress; Bradburn - Bradburn Affect Balance Scale; STA - State Trait Anxiety Inventory; GHQ - General Health Questionnaire; BSI - Brief Symptom Inventory; CIG-R - Clinical Interview Schedule; PS - Parenting Stress Index; QFS - Impact on Family Scale; RRS - Relatives Stress Scale; PSS - Perceived Stress Scale; CSI - Career Strain Index; LSI - Life Satisfaction Index; Family Impact Questionnaire; HQRS - Holroyd Questionnaire on Resources and Stress; Ham-D-14 - Hamilton Depression and Anxiety Scales; PANAS - Positive and Negative Affect Schedule

#### **4. Discussion**

Although methodological issues are discussed in detail at a later point in this review, it is important to mention at the outset that, in general, the research reviewed was methodologically poor. Problems that may have influenced findings such as a lack of control over variables, the absence of a control group, and insufficient sample sizes were common. In some cases, these problems were such that they would be likely to lead to the effects of respite being underestimated. The findings discussed below should be interpreted with this in mind.

Since the review sought to include quasi-experimental and observational studies, as well as draw from a wider pool of research that reflects the full range of ages and types of carers that respite is aimed at, studies were not assessed or rated on 'quality'. It was decided that a quantitative ranking or weighting system, if employed in an area of research that is characterised by a lack of high quality studies, would impose too much of restriction on the research that could be considered. It is, however, fully acknowledged that the implication of a lack of high quality studies and a weighted analysis restricts the confidence with which conclusions can be made.

##### **4.1 Who has been the subject of respite care research?**

The majority of carers included in the studies were female, which reflects the gender distribution of informal carers as a whole. Most studies also reported the relationship of the care-recipient to his or her carer. The findings indicated that the extent to which this potentially important variable was controlled differed according to whether the care recipients were children or adults. Studies

involving young care recipients were consistent in that, in most cases, 100% of the sample were caring for their own child. However, among studies concerned with adult care recipients, all but two included a varying mixture of relationships in the sample (mainly those caring for spouses and those caring for parents). The implications of this aspect of methodology are discussed later.

Aside from those studies concerned with carers of children, some form of dementia (especially Alzheimer's Disease) was by far the most frequently reported condition of the care-recipient. In many cases, however, the care recipients were simply described as 'elderly', leaving much doubt as to their care needs and the responsibilities placed upon the carer. Among the children being cared for, most were reported to have developmental or learning disabilities.

#### **4.2 Does respite lead to improvements in carers' well-being ?**

Before considering whether respite was found to improve well-being, it is important to consider the nature of 'improvement', or more generally, 'change' and how it was operationalised. The majority of studies in the review attempt to operationalise 'change' by including a 'time' variable which usually involves some level of prospective analysis in relation to different stages of the intervention (eg – pre- and post- respite). Fewer studies have additionally attempted to highlight 'change' by drawing comparisons with a control or comparison group not in receipt of intervention. It can be argued that both group and time variables are required before change can adequately be assessed.

Among the studies reviewed, the most popular end-point in the evaluation of respite was psychological well-being, operationalised through standardised measures of carers' depression, anxiety, mood or morale (33 studies). The

results of these studies suggested that respite intervention does not have a consistently beneficial effect, with 18 reporting improvements in psychological well-being, and 13 reporting no effect. One other study found improvements only among participants caring for patients with a stable (ie- non-declining) condition (Deimling et al., 1991). The final study (Pot et al., 2005) actually reported a decrease in well-being after in-home care was provided, although the authors make clear that this was likely to be an effect of selection bias, in that those carers experiencing the most impact of their role will accept and/ or apply and for intervention.

Studies also utilised measures more specific to the carer population (eg: carer stress or carer burden) (27 studies). Again, the findings seem rather equivocal, with 17 studies reporting improvements attributable to respite and 8 reporting no effect. One study, as before, found respite to only benefit carers of stable patients (Deimling et al., 1991), and the remaining study found both improvements and no change depending on the aspect of burden being examined (no change in levels of worry but improvements in levels of overload) (Zarit et al., 1998).

Only 5 studies examined the impact of respite on physical health, assessed via self-report measures such as symptom checklists. Just one study (of day care) reported an overall improvement in health (Hartiens, 1995). Three studies reported no effects of respite, and again, Deimling et al. reported improvements only among carers of a patient with a stable condition. One other study examined the effect on physiological functioning (Grant et al., 2003). In this study, plasma epinephrine declined significantly in the vulnerable caregivers who received respite.

The findings of this review suggest that the relationship between respite provision and the timing of outcome assessment may be an important consideration. In particular, several studies showed improvements of carers' psychological well-being during respite as compared to baseline measures (eg- Botuck & Winsberg, 1991; Adler et al., 1993; Larkin & Hopcroft, 1993). This benefit was, in some cases, maintained up to one week after the end of respite (Botuck & Winsberg, 1991, Caradoc-Davies & Harvey, 1995). Beyond one week, however, assessments indicated that psychological well-being or burden seemed to have returned to baseline levels. Larkin and Hopcroft (1993) for example, in their analysis of carers receiving a 2 week (residential) respite intervention, found that depression as assessed by the Brief Symptom Inventory (BSI) fell from a mean baseline level of 1.07 to 0.54 during the respite period, only to rise back to 0.92 a fortnight after the care-recipients' return home. The same pattern was found for several other BSI dimensions in this study as well as for overall scores. Similarly, Adler et al (1993) reported that subjective ratings of burden among carers fell during a respite period, but then increased back to baseline levels 2 weeks after discharge. Therefore, it seems that although respite intervention may sometimes lead to immediate improvements in carer well-being, these improvements fail to endure for long after respite has ended.

#### **4.3 Does respite delay the institutionalisation of the care-recipient ?**

Another way that the effectiveness of respite can be evaluated is the extent to which it influences the decision to permanently place care-recipients in a nursing home. This decision is largely influenced by the carer and is likely to reflect the burden they are experiencing (Zarit et al., 1986). Five studies looked at the effect of respite on carers' decision to permanently place the care-recipient in a nursing home. Two reported that respite exerted a positive effect (in that it prolonged the

time before, or reduced the likelihood of permanent institutionalisation) and one found no effect. The results of another study implied that respite encouraged permanent placement, although a clear conclusion is difficult due to the lack of a control group (Larkin & Hopcroft, 1993). Finally, one other study reported an interactive effect, with respite provision delaying placement among carers of parents, but encouraging institutional placement among spousal carers (Montgomery & Borgotta, 1989). From this limited evidence, therefore, it seems that respite has the potential to influence permanent institutionalisation but the direction of this influence remains unclear. The inconsistent findings may simply be due to the inconsistency with which respite proves effective in providing adequate relief from the demands of caring. Alternatively, it may reflect the fact that respite is sometimes very effective, but that this effectiveness in some cases serves to remind the carers of how much their life has been altered by their acquired role. In this way, by offering a stark contrast to normal daily demands, respite may positively encourage the decision to institutionalise.

#### **4.4 What factors influence the effectiveness of respite intervention?**

##### **4.4.1 Social factors**

Respite care may potentially alleviate carer burden and ill-health by facilitating the maintenance of socially supportive relationships, and hence the resources carers may draw on after respite has ended. The results of this review, however, suggest that this is not what commonly happens during respite. Twelve studies examined the impact of respite on the carers' social activity or support. Only 2 reported improvements due to respite while the other 10 found no change. One additional study reported deterioration in GHQ assessed social dysfunction during

the respite period (Homer & Gilleard, 1994) although the extent to which this can be considered a social support variable is debateable.

The fact that respite intervention often fails to enhance carers' social functioning was illustrated by Berry et al. (1991). Their analysis of carers' activity during respite suggests that although carers did use the respite time to get on with other work, they were not engaging in more social or family activity, and therefore not using the time to maintain relationships that may serve to support them in the future.

This may in part explain why any gains in well-being are often not maintained for long after the end of a respite intervention. In order for improvements to become less transitory it may be necessary that resources such as social relationships are reinvigorated during respite. This notion is supported by the fact that in both of the studies reporting an improvement in social activity and support due to respite, carers also exhibited improvements in all the psychological and / or burden variables assessed. In the study by Botuck & Winsberg (1991), carers spent more time in active social contact and exhibited improvements in psychological well-being at follow up a week after respite had ended. More recently, Cowen & Reed (2002) reported that a respite intervention that led to a decreases in carers' social isolation also led to decreases in overall stress and depression. In contrast, only 3 of the 7 studies that reported no change in social activity or support also reported improvements in either psychological well being or carer burden.

Engaging in social relationships and activities during respite may, however, be difficult as for many full-time carers social relationships deteriorate to a very low level during the period of care. Thus, interventions to facilitate social contacts and



relationships during respite may produce more long lasting effects by influencing carers' social resources. A good example is the study described by Hinchcliffe et al., which involved not only respite, but also a comprehensive programme tailored to individual carers' needs. One of the issues addressed was the development of independent social activities outside the home. Carers receiving this intervention exhibited a significant improvement in mental health (as assessed by the General Health Questionnaire) that was maintained at a 16-week follow-up.

It must be noted however, that to date, direct evidence of whether the extent to which the effects of respite on well being are to some degree moderated by it's effects on social activity or support is lacking. Neither is there any evidence that any additional supportive interventions combined with respite are directly responsible for any positive effects observed. These are matters for future research.

#### **4.4.2 Type of respite**

The studies reviewed reflect the diversity that exists in the form of respite care interventions offered to carers. The nature of the respite intervention fell into three main categories: residential respite care (including overnight care and evaluated exclusively in 14 studies), day care (11 studies), and in-home respite (which usually involved day-time visits from a nurse / care assistant) (13 studies). The remaining studies examined a respite 'package' that offered a choice or some synthesis of respite care forms.

Any comparison of the effects of the different types of respite must be treated with caution due to the small number of studies that could be placed exclusively in each category. However, there was some indication that certain forms of respite

produce more consistent positive effects than others. The number of studies reporting improvements in either psychological well-being or burden were examined. Residential respite was the most consistent in producing positive effects on the two most common outcomes (psychological well-being and burden), followed by day care and then in-home respite, which produced improvements in the lowest proportion of cases (see tables 6.4 and 6.5). Chi-Square analyses were performed in order to contrast the proportion of residential respite studies and in-home respite studies reporting improvements on well-being and burden (day care was omitted due to the small number of studies). The results indicated a significant effect in both cases, with residential care studies reporting improvements more consistently (Chi Square (Psychological Well-Being) = 4.34,  $p < 0.05$ ; Chi Square (Carer Burden) = 4.41,  $p < 0.05$ ).

**Table 5.4: Studies reporting improvement and no improvement in psychological well-being**

	Psychological Well-being		Total
	not improved	improved	
residential	2	7	9
in-home	7	3	10
day care	2	3	5

**Table 5.5: Studies reporting improvement and no improvement in carer burden**

	Carer Burden		Total
	not improved	improved	
residential	1	4	1
in-home	5	1	5
day care	1	4	1

This may indicate that the one factor in the success of a respite intervention is whether or not it provides night-time relief for the carer. There may be two

reasons for this. First, night-time respite may improve well-being simply by allowing the carer to sleep. Research suggests the prevalence of poor sleep related to dependency from the care recipient is high (Happe & Berger, 2002) and that it impacts on their psychological well-being (Carter & Chang, 2000). Any intervention allowing carers to experience a full night of sleep is therefore likely to be of great value to many carers.

Second, the effectiveness of services providing respite at night may also be due to the fact that they provide relief from early morning caregiving activities. As mentioned in the introduction, early mornings are often the most stressful part of the day for carers, in which several difficult tasks must be completed in a relatively short space of time (ie- getting the care recipient out of bed, dressing them and preparing breakfast). This is reflected in evidence suggesting that, for carers, the effects of stress on the stress hormone cortisol are most pronounced in the morning. Thus, overnight or residential respite services may be more effective because they provide relief from this difficult period.

One study also offered an insight into the relative value of day-care respite, through a comparison of carer activity during in-home and day-care respite periods. Berry et al. found that although in-home respite had the intended effect of reducing the amount of caregiving work, the day-care approach had the opposite effect, with participants spending more time in caregiving activity on respite days than on non-respite days. This is likely to be due to the preparations needed in the mornings before day-care begins, and also for the care-recipient's return back home in the afternoon.

While there is a suggestion that in-patient and overnight interventions may be more effective, it should be noted that no firm conclusions can be drawn regarding the relative effectiveness of various types of respite care. This would require a systematic comparison of different forms of respite within the same study. Such a study will have to carefully examine the effectiveness of different aspects of respite controlling for within group variation, as effectiveness is likely to be influenced by factors such as the quality of care provided and the attention paid to carer activity / attitudes.

The effectiveness of different respite care forms may also depend on the personal preferences of both carer and care recipient (which may in turn depend upon prior experience of respite). Given this premise, and in the absence of any clear evidence suggesting the superiority of any single respite form, it may be that a 'client centred' approach to respite provision that offers choice and flexibility to both carer and care recipient may be the best option.

#### **4.4.3 Care-recipient decline during respite**

Aside from reducing future strain by enabling time out and the ability to renew social relationships, respite also has the potential to increase future strain, in that it may create more problems to be coped with after the intervention period. In particular, if after respite a care-recipient's functional disability or need for care has increased, then this is likely to negate any improvements in carer well-being experienced during intervention, and prevent any enduring benefits (Brodaty & Gresham, 1992).

From the studies reviewed, there is some evidence for a moderating effect of changes in care recipient condition on the effects of respite on carers. Deimling (1991) reported an interaction between respite outcome and changes in the condition of Alzheimer's Disease sufferers. In this study, carers of stable sufferers showed a benefit, whilst those who declined did not. In addition, the interaction between respite provision and care recipient improvement on carers' well-being was tested directly by Gaugler et al (2003) who found carers using adult day services reporting decreases in memory problems also reported greater reductions in role overload.

Although it may be that changes in the care-recipient's condition during respite will moderate the intervention effects and the long-term benefit to the carer, the potential for respite to actually cause such changes is not clear. In chapter 3, previous studies investigating the effects of residential respite on care recipient condition were briefly examined. Overall, the findings were positive and indicated that respite care does not generally have a negative impact. However, any conclusions do have to be made with the caution. The provision of respite care across any society (just like in the case of any other health care service) will inevitably vary widely in both quality and impact on service users.

#### **4.4.4 Type of carer**

As mentioned in the introduction, one's relationship to the cared for person may have enormous consequences for how one experiences a caring role. This may also include how one experiences supportive intervention. In particular, the mechanisms and consequences of respite may differ widely between carers of parents and spousal carers.

Research has suggested that the carers most prone to the negative consequences of a caring role are spousal carers, (Brodaty & Hadzi-Pavlovic, 1990). Therefore, it may be expected that spouses would benefit more from respite since they are presumably in most need.

Unfortunately, relatively few of the studies considered the carer's relationship to the care-recipient. In fact, as mentioned earlier, many studies included in their sample a mixture of spousal carers and those caring for parents, without comparative analyses. Exceptionally, Montgomery and Borgatta (1989) found an interesting interactive effect between carer relationship and the probability of permanent nursing home placement. Institutionalisation was less likely if the carer was the adult child of the care-recipient, whilst the likelihood of placement in a nursing home was actually increased if the carer was a spouse. The authors point out that this is paradoxical as it is usually spouses who resist nursing home placement, while adult children are much more likely to accept the institutionalisation of their parent.

Since the review indicates that separate analyses such as this have rarely been performed in respite research then it may be that a lack of control over kinship relationship may lead to some effects of the intervention being obscured. Future research should aim to either control for kinship relationship in the design of the study or include sufficient numbers of different kinship groups in order to allow the detection of any differential effects.

One type of study that has more consistently exerted control over the relationship between carer and care recipient has been studies of parents caring for children

with special needs. These studies have tended to examine the effects of respite exclusively among this group and do not include spousal carers or those caring for parents. Since studies including the latter two groups rarely include carers of children a clear distinction can be made and comparisons drawn. On the basis of the studies in this review the efficacy of respite for carers of a child was compared to the efficacy of respite for other types of carers. Of those examining either psychological well-being or burden as an outcome, services aimed at carers of children produced positive effects in 90% of cases, while services provided for other carers led to reported improvements in only 55% of cases.

The seemingly greater efficacy of respite for carers of children may be due to a number of factors. First, the reasons may be due to the design of the evaluation. As mentioned earlier, studies of respite aimed at carers of children have been more exclusive in their inclusion to the study while other studies have exerted less control over the effect of kinship relationship (including both carers of parents and spouses). The differential experiences of the different types of carers in the later set of studies may have led to respite effects being obscured. Second,. the problems associated with caring for a child are more likely to be focused around behavioural issues (eg- hyperactivity) than are the responsibilities of carers of older patients (which generally include a wider variety of challenges such as memory problems and physical disability). Thus, the proportion of child respite services providing relief from behavioural problems may be greater than the proportion of adult services. Since behavioural problems have been identified as being the care recipient factor with the greatest impact on carer well-being, it may be that children's services have a greater overall efficacy since it is from this factor that they normally provide the most relief.

#### **4.4.5 Recent versus older studies**

While the effects of respite on carer well-being can not yet be said to be consistently positive, it may be that efficacy is improving with time. From the studies reviewed, it seems that more recent evaluations have produced more positive results. For example, if we examine the studies up to and including 1990 we find that only 30% reported improvements in psychological well-being and 25% reported improvements in burden. Post 1990, however, the findings are more positive, with 66% reporting improvements in psychological well-being and 88% reporting improvements in burden.

One possible interpretation is that the respite provision has improved. This may be due to respite planners and providers becoming more aware of carers needs, as well as becoming more effective in targeting those carers most likely to benefit from respite. Additionally, changes in legislation and societal attitudes over recent years may have ensured that carers involved in the later studies were more able to identify themselves as 'carers', as being entitled to support, and as able to take a break from their role without experiencing worry or guilt.

#### **5. What methodological issues influence the results of respite evaluation?**

As mentioned earlier, many of the studies suffered from serious methodological shortcomings. The nature of these shortcomings, as well as the effect they may have had on findings regarding the effectiveness of respite, is discussed below.



## **5.1 Use of controls**

Of the 55 studies under review, less than half (24 studies) were conducted with a control or comparison group (see table 1). The lack of a control group reduces the confidence with which changes in carer well-being can be attributed to respite intervention. Hence, in a number of studies under review, there is no clear evidence that the improvements reported in well-being were not due to some natural trend in participants' responses.

The lack of a control group also prevents examination of the preventive role of respite, since we cannot say anything about what would have been observed if no respite had been provided. Deimling (1991) reported that although carers of non-deteriorating Alzheimer's Disease sufferers experienced an increase in well-being over several months of respite availability, the well-being of carers looking after declining sufferers remained the same. Deimling suggests that respite intervention may have stabilised well-being that would otherwise have deteriorated in this latter group; a claim supported by the findings of Conlin et al.(1992), who reported a significant increase in stress among their control group. The absence of a control group in Deimling's study (ie- a non-respite group) prevents this conclusion being drawn with any confidence.

## **5.2 Allocation to groups**

Of the 24 studies with control or comparisons groups, only 6 randomly allocated participants. The vast majority of the others employed quasi-experimental designs (with allocation depending on factors such as date of discharge hospital, degree of dementia and position on waiting lists).

Practical and ethical barriers can make randomisation difficult. Respite care is increasingly considered to be a service provided as standard to both carers and care-recipients. To randomly deny carers access to such a standard service may be considered ethically problematic. Such ethical issues involved in exerting experimental control over access to respite may also lead to pragmatic difficulties. In particular, previous research suggests that respite providers or local carer organisations may be unwilling to involve their members in a project that intended to randomly accept or deny carers access to a standard support service such as respite (Greene & Monaghan, 1989).

Without randomisation, however, researchers are faced with a significant study design problem in that many of the variables influential over the allocation of groups may also influence the success of the respite intervention. For example, if group allocation is determined by self-selection, the effectiveness of respite is likely to be over-estimated due to the inevitably greater enthusiasm for respite in the treatment group. Respite offered to a randomly allocated group, including carers who may not necessarily have great confidence in its potential to improve well-being (and more representative of the population of carers in need of support), may not produce the same results.

Researchers need to control as much as possible for variables that may influence the effectiveness of respite, either through matching or statistical techniques. Using a waiting list control group may assist in achieving a degree of balance between groups. For example, attitudes to respite should be similar since the carers in both groups have applied to the scheme. Objective demands should also be similar since carers in both groups would presumably have met the same criteria for respite eligibility. However, the wide array of potential confounders

makes a balanced design difficult to achieve. What is more, analytical methods are limited because of collinearity, measurement error and residual confounding. This is a particular problem when, as in most of these studies, the sample size is small.

### **5.3 Uncontrolled variability in the use of respite**

The duration and frequency of respite care differed widely. The studies can be divided into those that evaluated the effect of one specific 'dose' of respite (usually residential and often of around 14 days duration), and those that evaluated the effect of a 'course' of respite provision or availability over a set time. In the latter group of studies, the amount of respite actually used by individual participants within the same sample often differed, making the intervention difficult to define and therefore evaluate. It is necessary to actually measure the use of respite as the availability of respite does not equate with utilisation. Many carers, for example, often have fears concerning the likely effect of respite on the care-recipient, which may discourage them from using the service (Rudin, 1994). Hence, it is possible that a 'treatment' group, even in a randomised investigation of the effects of respite, may not actually receive much treatment at all, which would in turn reduce the likelihood of finding a significant effect. An example from the studies reviewed is that of Lawton et al.(1989), in which only half of those participants who were offered respite intervention actually used it. This may explain, in part, why there was no significant association between change in well-being and membership of the 'respite' group. Whilst one could argue pragmatically that this reflects reality, as in "an intention to treat" analysis, it obscures our understanding of the potential adverse or beneficial effects of respite and how the current design of interventions can be improved.

Some studies wrongly assume that control participants are a 'non-respite' group. For example, in one intervention, the control group actually received as much respite as the treatment group (Oktay & Volland, 1990). Although this intervention did not rely on respite (as it also involved social work and nursing care provision) it serves to highlight the fact that respite research is carried out in the context of carers' social networks, from which support services are sometimes available whatever group they happen to have been allocated to in a study. Use of respite must therefore be carefully monitored, although this may be difficult in the case of 'informal' respite care (ie- that provided on a casual basis by friends and family).

#### **5.4 Sample size**

The effect of respite intervention may also be underestimated because of inadequate sample size. Respite is only one way of addressing the extreme demands of caring and can only be expected to have a moderate effect on carer burden and well-being. To detect a moderate effect size ( $d=0.50$ ) on a continuous outcome variable (with 80% power and alpha set at 0.05) 64 participants would be required in each group (Brodaty & Gresham, 1992). As suggested by the figures in table 1, this criteria is rarely met in respite evaluation. The samples differed widely in the number of subjects (range 4 - 632), and it is notable that over half of all the studies reviewed report total sample sizes of less than 64 (regardless of the number of groups). Such small studies are inadequate both in terms of descriptive statistics and more importantly for hypothesis testing. As statistical power is reduced so the chance of a type II error increases, making it likely that the prominence of inadequately sized samples in respite research has contributed to the inconsistency with which significant effects have been detected.

## **5.5 Sensitivity of outcome measures**

Another methodological issue is that current outcome measures used in respite research are often too insensitive to detect beneficial effects (Knight et al., 1993). It has been suggested that future work should develop more sensitive measures by broadening the range of possible responses in a scale. This may have the effect of 'decompressing' scores at the extremes of three or five point scales, and eliminating, or at least reducing ceiling and floor effects in participants' responses (Zarit & Toseland, 1989).

## **6. Conclusion**

Evidence of the efficacy of respite to enhance well-being among carers is not consistent. In particular, it seems that although carers often exhibit improvements in well-being during the respite period, these gains are short-lived. There may be several factors that influence the effectiveness of respite intervention. First, the extent to which respite facilitates the maintenance of socially supportive relationships, which evidence suggests is rare, may be important. Second, fluctuations in the condition of the care recipient during respite may also be crucial to whether or not gains in carer well-being endure. This may be particularly true in the case of behavioural dependency. Third, the form respite takes may be important to its effects. In particular, respite that provides night-time relief to the carer seems to be of much greater benefit than other forms of intervention.

In order to enhance the inconsistent efficacy of respite, a more holistic approach could be adopted to both the provision and evaluation of respite services. This approach would take into account factors such as the relationship of the carer to the patient, the activity of the carer during respite (particularly regarding their social network), and the effect of respite on the care-recipient. Other factors that

may be of interest include the attitudes of the carer to respite, feelings of guilt on behalf of the carer and carers' self-efficacy concerning their ability to make use of the respite time. Future work should also strive to avoid the many methodological problems common in previous respite research. In particular, studies need to employ well controlled experimental or quasi-experimental designs, have sufficient statistical power to detect clinically important differences, make clearer assessments of the nature and duration of respite receipt, employ more sensitive multi-dimensional outcome measures, and have sufficiently long follow-up assessments to determine the duration of any benefits. Without these improvements, the potential beneficial effect of respite for carers remains controversial.

## **Chapter 6: The Effects Respite Care on Carers:**

### **Rationale, Aims and Hypotheses**

#### **1. A summary of the study rationale**

#### **2. Rationale for the selection of outcomes**

##### **2.1 Physical Outcomes**

##### **2.2 Psychological Outcomes**

##### **2.3 Carer Burden**

##### **2.4 Social Outcomes**

##### **2.5 Care recipient outcomes**

#### **3. Research aims and hypotheses**

##### **3.1 Effect of age, sex and diagnosis**

##### **3.5 Relationships between outcome variables**

##### **3.6 Changes in care recipient condition**

##### **3.7 Effects of respite provision on carers**

## **1. A summary of the study rationale**

In the UK, the numbers of informal carers has grown to several million. Informal caring benefits society through the provision of care that would otherwise overwhelm national resources. However, a caring role has personal costs to the carers themselves. In particular, research has documented negative effects on both physical and emotional well-being. The support of carers and efforts to attenuate the impact of their role has therefore become a national priority.

The saliency of respite care as an intervention for carers has grown over recent years. It has been identified as the most commonly expressed unmet carer need and has been given a central place in UK government policy. The saliency of respite as an intervention and the extensive resources invested in its provision make it important to establish the efficacy of respite in achieving its aims.

## **2. Rationale for the selection of outcomes**

Official definitions of the aims of respite adopt a biopsychosocial approach, and see respite as having effects in terms of emotional & physical well-being, as well as on social functioning and, potentially, on the care recipient. Several options present themselves when considering the conceptualisation and operationalisation of these outcomes. The rationale for the selection of concepts for examination, based upon the evidence examined in chapters 3 and 4, is discussed in this chapter. The specific methods and instruments used to assess these concepts are described in more detail in the description of the study methodology (Chapter 7).



## **2.1 Physical Outcomes**

As discussed in chapter 3, outcomes relating to physical health include self-reported health, health care utilisation and reports on health status by health care professionals. While self-reported health will inevitably involve some degree of subjectivity (possibly reflecting psychological well-being) it can be argued that it is preferable to other outcomes when working with carers. For example, and as discussed earlier, health care utilisation outcomes in a sample of carers may reflect very little about the carer's physical health. This is because the use of services by carers has been found to be relatively low and determined by many other factors. Clinical assessment, on the other hand, is resource intensive while not offering any guarantee of greater validity. External evaluation is also arguably more conceptually distant from the well-being of the carer.

Self-reports of physical health may focus either on the experience of potentially transient physical symptoms (such as pain) or diagnosable, longer-term conditions (eg - arthritis). While diagnosable conditions will inevitably have more of an impact on the life experience of the individual, it is unrealistic to expect an evaluation of the short-term effects of one episode of respite care to reveal significant effects. Rather, it is likely that assessing symptoms would be more sensitive to change and better suited to the evaluation of single episode interventions. Therefore, it was decided to utilise carers' self-reports of physical symptoms in the present study.

Physical outcomes that may bypass the subjectivity inherent in self-report, as well as being immediate and sensitive to change, are those that relate to the functioning of certain physiological systems. As discussed in chapter 3, it is endocrine functioning lies at the fundamental level of the stress response. In

particular, stressed individuals may have continually elevated cortisol levels due to overactivity of the hypothalamic pituitary adrenal axis. Because of its fundamental relevance to the stress response, as well as the fact that it has been found to be elevated among carers (see chapter 3), and the potential it presents for *in situ* self-assessment (discussed more fully in chapter 7), cortisol was selected as an outcome in the present study.

## **2.2 Psychological Outcomes**

Concerning psychological outcomes, a common outcome in previous research has been depressive symptomatology. This outcome has many advantages. First, some of the most robust findings in relation to the effects of a caring role relate to depression (see chapter 3) so it is therefore relevant in the context of the present study. Second, depressive symptomatology has clinical significance, in that it reflects an outcome that goes beyond transient fluctuations in mood that can be viewed as part of 'normal' and healthy experience. Third, depressive symptomatology has the advantage of being measurable through the use of well standardised and validated scales that can be completed in a relatively short time and with minimal instruction. Therefore, self reported depressive symptomatology was selected as an outcome in the present study. The choice of instrument for the assessing this outcome is discussed in chapter 7.

## **2.3 Carer Burden**

As discussed in chapter 3, generic measures of well-being alone may fail to address many specific issues uniquely relevant to the care of a chronically-ill person. Therefore, it was decided that a measure of 'carer burden' should be added as an outcome in the present study. Since respite care may be seen as alleviating burden at both an objective level (eg - caring tasks) and a subjective

level (eg – stress) it was decided that both concepts such be included as outcomes. As discussed in chapter 3, carer burden and its effects on well-being may also be determined by appraisal, particularly in relation to the demands made by the care recipient. Therefore, it was decided that appraisals of caregiving demands should also be addressed in the evaluation of respite care.

## **2.4 Social Outcomes**

The importance of social support to the well being of carers has been extensively documented (see chapter 4). In considering the assessment of social outcomes, two main strands of work have emerged. The first has taken a structural approach and been concerned with the structures and objective features of individuals' social worlds, such as the number of identifiable social contacts or extent of social activity. A second line of work has adopted a more cognitive approach and has been concerned with social worlds as they are perceived and evaluated by the individual. Research among carers, as discussed in chapter 4, points to the importance of social contact and activity. This has been found to be a prominent influence in both carer well-being and the experience of respite care. Therefore, it was decided to focus upon this concept within the current study.

## **2.5 Care recipient outcomes**

In relation to care recipient outcomes, it is clear from previous work that is behavioural aspects of the cared for person's condition that is most likely to exert an effect on the caring relationship and carer burden (see chapter 3). It is also more likely that behavioural factors (such as aggression levels, confusion, etc) will be affected by a single respite intervention than more stable, physical aspects of functioning (eg – ability to walk or bathe oneself). Therefore, behavioural outcomes were selected for inclusion in the present study.

### **3. Research aims and hypotheses**

#### **3.1 Effect of age, sex and diagnosis**

In chapter one, evidence was discussed suggesting that the experience of a caring role is far from a homogeneous one. A number of factors were identified that may influence what a carer has to cope with, and in turn, the consequences in relation to their well-being.

In the present study, the effects of two 'characteristics' were specifically examined: the sex of the carer, and the diagnosis of the care recipient. First, given that men and women have been found to experience caring differently, and that research evidence seems to suggest that caring is a more 'all-encompassing' experience for women, it may be expected that female carers would exhibit poorer psychological well-being than men (Orbell 1996, Twigg 1992). Second, in view of the findings of previous studies suggesting that carers of dementia sufferers report a greater psychological impact of their role than carers of non-dementia sufferers (Rainer et al, 2002), as well as evidence that problematic behaviours are acknowledged as some of the earliest and most common changes among persons with dementia (Petry et al, 1988, Burns et al, 1990), it was expected that carers of people with dementia in the present study may exhibit poorer well-being than carers of people with other conditions.

*Hypothesis 1: Self-reports of depressive symptoms would be higher at baseline among female carers than among male carers.*

*Hypothesis 2: Self-reports of depressive symptoms would be higher at baseline among carers of people with dementia than among carers of people with non-dementia conditions.*

### **3.2 Relationships between outcome variables**

The second aim of the present study was to examine the interaction between outcome variables. First, the relationship between the various self-report measures of psychological, physical and social outcomes was of interest. As discussed in chapter 3, reports of psychological well-being may to some degree reflect an underlying perceptual factor that will also influence reports of physical health and of social well-being.

Second, little is currently known about how physical and psychological indices of well-being are related. In particular, there is a need for a greater understanding of how self-reported well-being may relate to more direct assessments of physiological functioning in the context of chronic stress. One may expect, however, that since cortisol is a marker of the stress response, it would be positively associated with reports depressive and physical symptoms.

*Hypothesis 3: Self-reports of physical symptoms, depressive symptoms and carer burden would be positively inter-correlated.*

*Hypothesis 4: Self-reports of physical symptoms, depressive symptoms and carer burden would be negatively correlated with reports of social activity.*

*Hypothesis 5: Self- reports of physical symptoms, depressive symptoms and carer burden would be positively correlated with cortisol levels.*

### **3.3 Changes in care recipient condition**

People with dementia often function best in a familiar environment. Environmental change can be disruptive and cause symptoms to worsen (Lawlor, 1997). Therefore, one may expect that residential respite care would have the potential to disorientate individuals suffering from dementia, and have at least a short-term effect on their behavioural condition. However, research on the effects of respite on care recipients condition have, to date been mixed and, if anything, positive (see chapter 3). While some studies have indeed found respite to exert a detrimental effect on behavioural functioning (eg – Hirsch et al., 1993) others have observed no effect or even improvements in condition due to respite (eg - Neville & Byrne, 2006). Therefore, in order to add to this literature, and in respect for the need for a 'dual focus' in evaluating interventions, an additional aim of this present study was to examine the effects of respite intervention on care recipients.

Evidence was discussed in chapter 3 suggesting that behavioural problems exhibited by the care recipient are a major factor in determining carers well-being. Poor behavioural functioning may impact not only on the carer directly (such as affecting sleep) but also impact on their social resources that in turn help them to cope with the stress they are under. However, little is known however, about the immediate effects of short-term *changes* in behavioural functioning on carers. In particular it may be changes in condition that have an impact, with longitudinal

research findings suggesting that both the mental and physical health of carers are significantly affected by increases in patients' problematic behaviours.

*Hypothesis 6: Care recipients with a diagnosis of dementia who also experienced respite care would exhibit a greater increase in dependency (from times 1 to 3) than those not receiving respite and/or with no dementia diagnosis.*

*Hypothesis 7: Carers reporting an increase in the behavioural problems exhibited by their care recipient (from times 1 to 3) would report, at follow up, greater levels of depression, physical symptoms and burden than carers reporting no change or a decrease in behavioural problems (after controlling for baseline levels of behavioural problems and outcomes).*

### **3.4 Effects of respite provision on carers**

The primary aim of the present study was to investigate the effects of respite care on carers' well-being. From the evidence discussed in the literature review in chapter 5, it seems likely that the efficacy of respite to enhance well-being among carers is not consistent. First, improvements in carers' well-being during the respite period are unlikely to be permanent, and it is important to attempt to gauge the stability of 'gains' derived from respite through the use of multiple follow ups so that it's provision can be planned more appropriately.

Second, the literature review findings also suggest that there may be factors that influence the effectiveness of respite. First, the extent to which respite facilitates the maintenance of socially supportive relationships, which evidence suggests is rare, may be important. Second, fluctuations in the condition of the care recipient

during respite may also be crucial to whether or not gains in carer well-being endure.

*Hypothesis 8: Carers in receipt of respite during the study period will exhibit lower levels of depressive symptoms; physical symptoms; carer burden and cortisol at follow up than carers not receiving respite care (after controlling for baseline levels in outcome measures).*

*Hypothesis 9: The positive effects of respite on carers' well-being will be greater among carers reporting an increase in social activity during the first fortnight of assessment than among carers reporting no change or a decrease in social activity.*

*Hypothesis 10: The positive effects of respite on carers' well-being will be greater among carers reporting an improvement or no change in their care recipient's dependency from pre to post respite than among carers reporting a deterioration in dependency.*

The study design utilised to test these hypotheses, along with the selection of assessment instruments, sampling method, study procedures and statistical methods are discussed in the following chapter.



## **Chapter 7: Methods**

### **1. Design**

- 1.1 Intervention**
- 1.2 Experimental Control**
- 1.3 Design Of The Present Study**

### **2. Sample**

- 3.1 Criteria**
- 3.2 Sampling & Recruitment**
- 2.3 Sample Size**

### **3. Measures**

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## **1. Design**

### **1.1 Intervention**

While one option in addressing the effects of respite care upon carers would be to examine outcomes over several years, the extent to which respite care is now a standard intervention available to the vast majority of carers would make finding a comparison group of carers with similar circumstances but not using respite care difficult. Therefore, it was decided in the present study to examine the relatively short-term effects of one episode of respite provision.

As discussed in previous chapters, respite care is provided to carers in a number of forms (eg- residential, home based & day care). However, it was decided that the form of respite should be held constant in the present study and that only one type of intervention should be examined. While this approach inevitably reduces the extent to which findings can be generalised, it does serve to control for confounding effects due to the potentially different ways in which various forms of respite exert their effects.

Residential respite was selected as the intervention to be examined. One reason for this choice was that, compared to home-based respite and day care, residential respite results in a more complete and longer-term absence of the care-recipient from the carer. For this reason, an '*in situ*' analysis of carers' response during the actual respite period (rather than merely pre and post respite assessment) was most feasible with this form of intervention.

Residential respite was also selected as the focus of the present study as it is likely to be the most expensive form of respite to provide, thus making it a priority

for evaluation. The high costs are due to many factors, including the number of staff involved and the 24-hour nature of the care required. Indeed, from the perspective of national resources, the high cost of residential-care over community-based care is one consideration that makes the support of carers a national priority.

## **1.2 Experimental control**

It could be argued that the ideal design to assess the efficacy of respite care intervention would be a randomised controlled trial (RCT). This would, in theory, produce experimental and control groups equal in terms of all extraneous and potentially confounding variables.

Randomisation in this case may, however, may have posed serious ethical and pragmatic problems. Respite care is increasingly considered to be a service provided as standard to both carers and care-recipients in the UK. Indeed, as mentioned in an earlier section, public policy in the form of the 1999 National Strategy for Carers places respite at the very heart of carer support in the UK. To randomly deny carers access to such a standard service may be considered ethically problematic.

The ethical issues involved in exerting experimental control over access to respite may also lead to pragmatic difficulties. In particular, previous research suggests that respite providers or local carer organisations may be unwilling to involve their members in a project that intended to randomly accept or deny carers access to a standard support service such as respite (Greene & Monaghan, 1989).

One alternative to relying on existing respite agencies would have been to actually establish and provide a respite service dedicated to the purpose of determining respite efficacy. However, aside from failing to avoid the ethical issues already discussed, this would have involved enormous resources, both in terms of time and funding, which would have been beyond those available.

Aside from pragmatic and ethical issues, experimental control (involving randomisation or not) may not necessarily eliminate confounding variables in the case of respite care intervention. For example, allocation to a control (non-respite) group may have had a negative effect on carers that would have been likely to influence outcome. Respite, unlike many interventions less well known to carers, is a highly desirable service and is the most frequently reported unmet need among carers in the UK (Kersten et al, 2001). Denial of any highly desirable intervention by a research team (either through randomisation or any other process) would be likely to give rise to disappointment and resentment towards the project among the control group. This in turn may negatively influence responses to assessment as well as increase drop out in this group, thus biasing the results.

Furthermore, control over access to respite would inevitably have required close collaboration with the agency providing the respite service (eg- nursing home or hospital ward). Awareness among respite staff of the fact that the effects of respite services on carers and care recipients were being evaluated may well have biased the standard of service being provided. Extra efforts may have been made to provide an exceptional service to individuals involved in the study, thus leading to a level of intervention atypical of the respite care normally provided.

One possible option for avoiding the negative effects of control group allocation would be to introduce a waiting list control, with participants assured of access to respite at a later date. To some extent, carers in the control group of the present study were a waiting list control as they all met the criteria for the provision of respite care (full-time carers of a chronically ill spouse living at home). However, to only include carers in the control group if they had actually had their next date for respite set would have introduced serious pragmatic issues. For example, many carers are given limited notice of their next date for respite and there will often not have been enough time to conduct the four assessments between the time they were given the respite start date and the start of the respite period.

### **1.3 Design of the present study**

It was decided, therefore, that the present study employ an observational approach to examine the efficacy of respite. The effects of intervention in the form of the services already forming part of individuals' community care plan were the subject of evaluation. Collaboration was with carer groups rather than with respite providers and respite provision was explicitly not within the control of the research team.

A repeated measures design was employed incorporating assessment at four time points with carers receiving respite in comparison to concurrent controls. In relation to the criteria for group allocation, participants were 'allocated' to the respite group if they indicated that a respite period was scheduled within the next two months. All other participants were allocated to the control group. The design was multi-factorial in that the potential moderating and/or mediating effects

of changes in carers' social activity and care-recipients' dependency were examined.

Assessments of psychological and physiological well-being were made at four time points in relation to a residential respite period lasting more than seven days.

These time points were:

- Time 1: 2 weeks before respite
- Time 2: the mid-point of the respite
- Time 3: 1 week after the end of respite
- Time 4: 3 weeks after the end of respite

The latter two follow-up assessments were made at these times in order to address the findings of the literature review concerning the maintenance of gains in well-being beyond one week after respite. Assessments were made with a control group according to a time frame designed to reflect assessment in the respite group. Control assessments were scheduled to mirror the receipt of a 14-day respite intervention (a common duration).

Assessments were therefore conducted at baseline (scheduled on a day convenient to the participant), and then again at 21 days, 35 days and 49 days after this baseline assessment (see table 7.1). Whenever possible, assessments with both groups were scheduled at the same time of day in order to control for any effects on psychological or physiological responses.

**Figure 7.1. Schedule of assessments in respite and control groups**

<b>Assessment</b>	<b>RESPITE</b>	<b>CONTROL</b>
Time 1	(start of respite <i>minus</i> 14 days)	T1
Time 2	(mid-point of respite)	(T1 <i>plus</i> 21 days)
Time 3	(end of respite <i>plus</i> 7 days)	(T2 <i>plus</i> 14 days)
Time 4	(end of respite <i>plus</i> 21 days)	(T3 <i>plus</i> 14 days)

## **2. Sample**

The study was conducted in a community setting with carers throughout London and the Home Counties. Ethical approval was sought and obtained from the UCL Research Ethics Committee.

### **2.1 Criteria**

All participants were full-time, carers of a spouse with a chronic illness living at home. Only full-time (co-resident) carers were included since it is at this group that respite provision is usually aimed. It can also be claimed that, since full-time carers are likely to be under a higher level of demands and stressors than part-time or non co-resident carers, they are a priority in terms of the development and improvement of all forms of intervention.

Three main kinship categories can usually be identified among the population of carers: those caring for a parent, those caring for a child, and those caring for a spouse/partner. It was decided that only one of these groups should be included so as to control for the very different demands faced by different types of carers, their potentially different expectations of the relationship and caring role and the potentially different ways in which interventions may effect their well-being (Zarit and Toseland, 1989).

Spousal carers were decided upon for two reasons. First, research has suggested that spousal carers are the most prone to the negative consequences of a caring role (Brodaty & Hadzi-Pavlovic, 1990), and may therefore be a priority in terms of the provision of effective intervention. Second, the family structure of spousal carers tends to be more consistent as in most cases, the couple are elderly and do not have children (or other dependents) living at home. In the case of parental and child carers, the varying presence of partners and other dependents (parents & children) would have led to a highly variable family structure which would have been difficult to control.

Carers were excluded if the care-recipient had been away from the home (or the carer) for more than 24 hours at anytime other than the scheduled respite intervention during the period the carer was enrolled in the study (ie- from 2 to 3 weeks before visit one up to visit 4). Unscheduled gaps in the carers' demands such as this may have been due to extra respite provision, or a hospital visit by either partner and may potentially influence any effects of respite. This exclusion criteria applied to carers in the control group as well as the respite group.

Only carers able to complete the interviews in English were included in the study. This criteria became necessary partly due to the standardisation of some of the instruments used, the difficulties of employing a translator and the limited language abilities of those collecting the data. It is acknowledged that the sample studied did not therefore reflect variety of cultural groups involved in informal caring.



In both of the study groups (respite and controls), participation in the study did not commence until two months had passed since the previous respite care period so as to reduce the effects of prior respite provision on outcome.

## **2.2 Sampling & Recruitment**

Carers were recruited via the mailing lists of several local carers support centres around London & the south-east of England. The majority of these centres were funded by the Princess Royal Trust for carers. This organisation provides a range of services to carers registered with them, including information, advice and social activities.

Carers were initially contacted via an advert or flyer inviting them to volunteer for the study. The information regarding the study was mailed out to carers as well as displayed in carer support centres and included in publications related to informal caregiving. A phone number was provided for those interested in finding out more. Carers calling the number were given more details about what the study would involve, and if appropriate, four visits were scheduled according to the method described above.

The method of recruiting carers from the lists of support organisations may potentially create a sampling bias. As Schulz et al.(1990) point out, samples recruited from local support societies may be biased towards the more distressed members of the carer community. This may be because each carer member, at one point, felt that their demands were such that they needed external help and support, which prompted their decision to register.

However, this conclusion is rather one-sided in that it fails to recognise that the bias may well work both ways. While distress may have initially prompted support organisation membership, continuing membership and the support that accompanies it is likely to alleviate burden, thus creating a bias towards the less distressed carers within the population. What is more, for a carer to join a support organisation and maintain membership essentially requires a certain level of motivation which may be lacking among the more distressed carers in the community.

### **2.3 Sample size**

There are a number of ways in which to calculate the sample size required to detect the effects of any given intervention. One option is to look back at previous studies for an estimation of the effect size usually produced by the intervention of concern. This requires that data is available from studies of the same intervention utilising similar outcomes. Alternatively, another option is to identify the magnitude of difference on an outcome measure that would be clinically as well as statistically significant (ie – the difference between 'normal' and 'clinical' levels on an outcome). This can be achieved by taking the difference between the 'healthy population' mean on a well-established outcome measure (as found in previous, large scale surveys) and the established 'cut off' point for 'caseness' on that measure (ie- the score at which a clinical diagnosis becomes likely).

Since previous studies of respite care have showed wide variability in outcome measures, intervention type and designs, an estimation of the expected effect size based upon previous work would be difficult (Arksey, 2004). Therefore, it was

decided to base the sample size calculation for the present study on the number required to detect a clinically meaningful difference.

Power calculations were performed on one of the primary outcome measures - depression (as assessed by the CES-D). A clinically meaningful difference on this scale would be that between the average score for community based, non-depressed adults, and the 'cut off' score for possible clinical depression (cut off score = 16) (Radloff, 1977). In a sample of 1372 randomly selected people from a population register, Scott & Melin (1998) reported a mean score on the CES-D of 10.70 (with a standard deviation of 7.56). This differs from the 'cut off' score of 16 by 5.30 points. In order to detect a difference of this magnitude (or larger) with both alpha (chance of a type I error) and beta (change of a type II error) set at 5% (and so power set at 95%) a sample of 90 participants was required. Data were collected from a total of 112 participants at baseline, which allowed for a 20% dropout rate.

### **3. Measures**

A number of measures were employed to assess outcomes (dependent variables) intended to evaluate the efficacy of respite care, while others were included as 'third variables' in order to allow examination of factors that potentially moderate or mediate the effects of respite. Additional measures were included for the purposes of the secondary aim of the study that is, identifying the correlates of outcomes among the sample as a whole at baseline.

### 3.1 Outcomes

Earlier chapters considered the distinction between generic or carer specific measures. Generic instruments have the advantage of allowing comparison between carers and other, non-carer populations. This allows findings relating to carers to be placed in a wider context and the effects of caring to be viewed relative to the effects of other sources of chronic stress. However, generic measures may miss particular aspects of a caring role that have an impact, and as a result, be insensitive to the impact of a caring role on well-being. For these reasons, it was decided to employ both generic and carer-specific measures of psychological well-being in the present study. An overview of the outcome measures included in the study is presented in table 7.2.

**Table 7.2: Outcome measures used in the present study**

<b>Concept Type</b>	<b>Concept</b>	<b>Instrument</b>
<b>Generic:</b>	Depression	Center for Epidemiologic Studies Depression Scale (CES-D)
	Reported Symptoms	Symptom Checklist
	Cortisol	12 hr Secretion (Saliva)
<b>Population Specific:</b>	Subjective Carer Stress	Montgomery-Borgatta Caregiver Burden Scale
	Subjective Carer Demand	Montgomery-Borgatta Caregiver Burden Scale
	Objective Carer Burden	Montgomery-Borgatta Caregiver Burden Scale

### **3.1.1 Generic Measures: Psychological Well-Being**

Virtually all studies of the effects of informal caring have included measures of psychological well-being. A large and consistent body of evidence has accumulated suggesting that there are real consequences of a caring role in terms of psychological distress, often to a level considered clinically significant (Schulz et al., 1990).

There are a number of standardised scales specifically designed to assess psychological well-being. Several instruments are examined in chapter 3, in which concerns around clinical significance and applicability to community samples were addressed.

A concept that has both clinical significance and community applicability is depressive symptomatology. Depression is one of the most common disorders of old age (Blazer, 1989) making it a particularly relevant outcome in a study of spousal carers. It is also a commonly found disorder within the caring population as a whole, with levels reaching far beyond those found in the general population (Schulz et al., 1995).

A measure that has both a cut off point for a 'clinically significant' level of symptoms, as well as having been developed within community samples is the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). The CES-D is an extensively used 20-item scale of depressive symptomatology over the past week. The scale was designed to assess symptoms of depression in the general (ie- non-clinical) population. The internal and test-retest reliability of the CES-D have been demonstrated along with the ability of the scale to discriminate well between general and psychiatric samples (Radloff & Locke 1986).

The CES-D has been extensively used among community based elderly samples, within which its reliability and validity have been confirmed (Beekman, et al. 1997). While scores on other measures of depression or negative mood state have shown a tendency to significantly decrease with repeated administration (eg- Beck Depression Inventory; Profile of Mood States) the CES-D has been found to be more stable across consecutive assessments (Sharpe & Gilbert, 1998).

### **3.1.2 Generic Measures: Physical Well-Being**

While the findings of research investigating the consequences of caring in terms of psychiatric morbidity have shown consistent effects, there has been less consensus concerning physical health outcomes (see Schulz et al. 1990; Schulz et al. 1995 for reviews). As discussed in the respite literature review there is similarly less evidence concerning the effects of interventions aimed at caregivers on physical outcome.

The method of asking participants to report on their own health may be criticised for the subjectivity involved. However, the inclusion of such subjective reports as outcome measures does have validity in the light of the problems inherent in 'objective' data (Bowling, 1991). A checklist of physical symptoms experienced over the last week (eg- headaches, nausea, dry throat) was included in the present study (Cox et al., 1987). Participants were simply asked to respond yes or no to whether they had experienced each symptom. The extent to which this measure is truly a physical outcome rather than a psychological outcome is open to debate. Complaining about these physical correlates has been suggested to

be a good marker of depression rather than physical ill-health (somatising) (Stansfeld, Smith & Marmot, 1993).

A way of disentangling physical outcomes from subjective bias is to directly assess physiological functioning. A number of physiological systems may be examined in the course of research, often using techniques that are relatively non-invasive to the participant (see chapter 3 for review).

Chronically stressed individuals (such as carers) may have continually elevated cortisol levels due to over-activity of the hypothalamic pituitary adrenal (HPA) axis (Vedhara et al., 1999). This elevation of total cortisol exposure may have significant metabolic cost to the individual, (eg Brindley & Roland, 1989) and increase the risk of both acute and chronic disease. Cortisol secretion is also a particularly appropriate outcome in this study because of its well-documented association with social support (Uchino et al, 1994).

For assessment purposes, salivary cortisol accurately reflects the concentration of unbound (and therefore biologically active) cortisol in the blood. It has been shown to be a reliable measure of more sophisticated endocrine function tests (Uchino et al., 1994). A major advantage is that saliva sampling is relatively non-invasive (eg- compared to blood sampling) making it unlikely that data collection itself will produce a stress response. Saliva sampling is also easily achieved (after instruction) by participants and may therefore be carried out *in situ* and in the absence of the researcher.

Secretion during the twelve-hour assessment periods was monitored using self-administered salivettes (manufactured by Sarstedt, Germany). This method

simply involves the subject chewing gently on a small cotton wool roll for around 60 seconds, which was practiced in the presence of the researcher. Four samples were taken on the day after all four visits (at 10:00; 14:00; 16:00; 22:00). Samples were stored in the participants' own refrigerator overnight, and then posted directly to the laboratory for analysis. Similar methods have been used successfully by other researchers (eg- Ockenfels, 1995). Details of the saliva analysis are given in the procedure section below.

### **3.1.3 Population Specific Measures: Carer Burden**

The multi-dimensional nature of the burden faced by carers, as well as how carer burden has been conceptualised in previous research, was discussed in chapter 3. It was concluded that, while many of the instruments that have been used to assess carer burden include both objective and subjective elements, few manage to draw out distinctions between the traditional stimulus response concepts of objective burden and subjective reaction and carers' appraisals of burden. In particular, most measures do not address (as a separate dimension) appraisals by the carer of the care recipient's behaviour. Therefore, the objective demands intrinsic to the caring role have usually been assessed without reference to whether or not carers actually assess these demands as burdensome or reasonable.

The Montgomery-Borgatta Caregiver Burden Scale has been used in previous respite evaluation studies by its authors (Montgomery et al, 1995) and was selected for use in the present study. It covers three distinct dimensions of carer burden: objective burden (effects of caring on time, privacy, social life); subjective stress (anxiety, stress, tension, nervousness), and also subjective demand



(appraisals of caring demands as unreasonable or of being taken advantage of). The authors report good internal consistency for each scale (Cronbach's Alpha = 0.91, 0.88, 0.88 for each scale respectively).

One major concern levelled at all measures of carer burden in previous work relates to their sensitivity to change (Knight et al.1993; Zarit & Toseland, 1989). In particular, a recent review concluded that carer burden scores as an outcome seemed resistant to fluctuation in intervention studies (Cooke et al, 2001).

Applying this to the responses available in the Caregiver Burden Scale, it may be that a participant giving a rating of 'A Great Deal' in relation to an aspect of burden before intervention may experience a decrease in that burden post intervention. However, despite this decrease, the remaining level of burden may be such that it is still considered by them to be 'A great deal' and hence the data would show no change.

Zarit & Toseland (1989) suggested more sensitive measures should be developed to address this issue. One possibility they raised was to alter responses in a scale that may be responsible for ceiling effects. In the present study, the Caregiver Burden Scale was adapted slightly to allow carers to indicate a perception of change from a 'normal' level. That is, instead of rating their level of burden in the original absolute sense (eg- 'not at all' to 'a great deal') carers were asked to rate their burden (in the last week) as to whether it had been 'a lot less than usual' to 'a lot more than usual'. The original scale was also administered at baseline alongside the adapted version for the purposes of validation. The relationship between the two, along with the internal and external reliability of the new measure was examined and reported in chapter 9.

### **3.2 'Third Variable' factors**

From the review of previous studies examining respite care (see chapter 6) it is evident that respite does not have a consistent and linear effect on outcome. Rather, like any intervention operating in a complex social environment, its effect is likely to be influenced by a range of social and / or psychological factors that will serve to enhance or reduce its effectiveness.

Baron and Kenny (1986) used the term 'third variable' to describe any factor that may either moderate or mediate the effect of one variable on another. A third variable can be said to moderate the effects of an intervention when the strength and/or direction of those effects differ at different levels of the third variable. A moderating effect does not imply that the intervention 'works through' the moderating variable. A mediator, however, is directly part of the causal process, and is in effect responsible (or at least partly responsible) for the effect of intervention on outcome. Methods for testing for moderating and mediating effects are discussed further in the section on statistical methods.

In selecting which 'third variable' factors to include in the present study two criteria were employed. First, in order for the study to be consistent with the aims of respite care provision in the UK, it was decided to examine factors that are addressed within official statements on the intended effects of respite. Second, factors should be selected for examination on the basis that they have emerged as potentially important variables in previous work on respite.

In relation to the first criteria, the *National Strategy for Carers* (DH, 1999) makes clear that, apart from the immediate intention that "a break from caring is

invaluable in reducing the psychological and emotional stress faced by many carers", respite should allow carers "time to pursue their own interests, see their own friends, cinema or have a meal out", while not resulting in the "taking away any of the rights of the people who need care, nor recognising their needs any the less" (see chapter 2 for full discussion).

Second, from the literature review in chapter 5, two factors emerged that may influence the effects respite has (although the influence of these factors had not been directly tested in a multi-factorial design). The first factor relates to the social support of the carer, and in particular, the extent to which respite influences social activity. The second concerns changes in the condition of the care recipient over the respite period.

### **3.2.1 Social activity**

As discussed in chapter 4, the term 'social support' has become an umbrella term to describe a wide range of phenomena. This ranges from the subjective, personality based concepts of social support, to fairly objective and structural conceptualisations. As Sarason & Sarson (1990) point out, perceived social support may be a relatively stable factor owing as much to early attachment experiences as to current experiences of social interaction. Thus, while playing a crucial role in the determination of health and well-being, perceived social support may not be a variable sensitive to the effects of a relatively short –term intervention such as respite.

More appropriate for detecting the effects of respite may be more structural measures of social support, such as those tapping into the actual social interactions that occur in individuals' daily lives. Aside from being previously

identified as maybe the most important social support factor in determining carers' well being (Thompson et al., 1993), social activity is likely to be responsive to the short term changes in carers' daily routine that could potentially result from respite (such as more free time or no home-based responsibilities).

Therefore, it was decided to examine fluctuations in social activity as a potential moderator or mediator of the effects of respite. As no standardised tools for assessing social activity were identified, the research team developed a 12-item checklist of social events. The checklist asked participants to estimate the number of times they had engaged in each activity listed in the last seven days (see appendix). The internal and external reliability of the checklist was examined and is reported in chapter 8.

### **3.2.2 Care Recipient condition**

Brief information was sought from the carer in relation to diagnoses that had been confirmed (by a clinician) in relation to the care recipient. While it may be argued that this method of confirming the nature of diagnosis through the carer and not through the care recipient him or herself is unnecessarily indirect, it was adopted for a number of reasons. First, in many cases the researchers were unable to confirm the diagnosis with the care recipient due to communication difficulties. Second, discussions with carers groups before the study began revealed that many carers would be unwilling to take part in a study about respite care in the presence of the person they care for. In some cases, for example, carers felt that if they were take part in the study then they would like to be able to speak freely about their caring role and the burden they were under, and felt that this would not be possible in the presence of the person they care for.

As discussed in chapter 3, there are many aspects to the condition of any chronically ill person, and it is important to go beyond a simple diagnosis. One distinction that can be drawn is between instrumental, self-care aspects (often referred to as 'activities of daily living' or 'ADL') and more psychological, behavioural aspects. As already discussed, there is strong evidence to suggest that that it is behavioural dependency that is most predictive of caregiver well-being.

One important consideration related to care recipient condition is the potential for fluctuation. Short-term deterioration in the condition of patients with chronic illnesses such as dementia is common and may potentially negate the benefits of respite intervention (see literature review). Thus, in examining dependency as a moderator of respite, change was examined rather than simply absolute levels of dependency. Assessments relating to the care recipient were only administered at visits 1, 3 and 4 since (for the respite group) the care-recipient was away from the carer at visit 2.

The Clifton Assessment Procedures for the Elderly (CAPE-BRS) (Pattie & Gilleard, 1979) was selected for use on the present study. The CAPE is the most extensively tested measure of dependency in widespread use in the UK (Bowling, 1995). The Behaviour Rating Scale (completed by the carer) incorporates 18 items. All but four items relate to behavioural aspects such as night time activity and anti-social behaviour (with the other four relating to incontinence and activities of daily living).

The scale is specifically designed to be completed by a third party who knows the subject well. Internal reliability has been demonstrated to be high (Pattie & Gilleard, 1979). The concurrent validity of the CAPE as a whole has been examined and it discriminates significantly among patients with severe, moderate, mild and no dementia as well as distinguishing between patients with dementia and those with physical impairment (McPherson et al., 1985).

### **3.5 Carers' Evaluation of Respite**

In addition to the measures of well-being, it was decided to administer an instrument aimed at assessing carers' own evaluations of the respite care intervention. The intention was to shed some light on the relationship between carers' satisfaction with the intervention and measured changes in their well-being due to the intervention, as well as to examine what factors may underlie carers' evaluations of respite care.

A scale was developed that asked for carers' responses on a 5-point Likert in relation to 14 statements about how the respite period had gone. While some items pertained to their own experience of respite, others related to how they saw respite as having affected their care recipient (see appendix). The items were scored 1 to 5, with some of the items reversed scored so that a higher score indicated higher satisfaction). The scale was administered to carers (in the respite group) 1 week following the return of the care recipient (time 3).

## **4. PROCEDURE**

The procedures for sampling and the recruitment of participants are described in section 2 of this chapter. The procedures employed for data collection, cortisol analysis and statistical analysis are discussed below.

### **4.1 Data Collection**

On consenting to take part in the study interview dates were arranged. Each of the four interviews were conducted in caregivers' homes and followed exactly the same procedure. The researcher, who read out each item to the participant one by one, completed questionnaires. This method was employed since it was anticipated that a proportion of participants may experience difficulties with reading a lot of text in one session (eg- due to poor eyesight). However, the questionnaires were in full view of the participant at all times and they were encouraged to look at each item as the researcher read it out.

It is important to note that the interviewers were not 'blind' to the group allocation of the participant. Rather both interviewer and participant were aware of whether or not respite care was taking place during the study period. In order to minimise the effect of this on outcome, the interviews followed a pre-agreed and standardised format in which the same information was given to all participants and questions were asked in the same way.

At the end of the interview participants were instructed in how to use the salivettes for collection of saliva samples. They were instructed to use the salivettes at the scheduled times the next day (10:00; 14:00; 18:00; 22:00), placing used salivettes in their refrigerator. A padded, stamped addressed envelope was left with the

participant for posting the salivettes to the laboratory on the morning following their use.

#### **4.2 Cortisol analysis**

Upon arrival in the laboratory the sample salivettes were frozen at  $-20^{\circ}\text{C}$  until assayed. On the day of the radioimmunoassay, samples were thawed at room temperature and centrifuged at 3000 rpm (1900g) for 15 minutes. Saliva (25ml) was added in duplicate to wells which contained 25ml buffer (0.02mM Sodium Citrate, 0.049mM Sodium dihydrogen orthophosphate dihydrate,  $\text{H}_2\text{O}$ , BSA (100mg/100mls) at pH 7.2-7.4), 25ml antibody (Bioclin Cortisol-3-OCMO Antiserum (R), sterile  $\text{dH}_2\text{O}$  was added to each vial to make stock 250ml of which was then added to 10mls of buffer) and 25ml  $^{125}\text{I}$ -Cortisol (7-8,00 CPM/well,  $\sim 74\text{TBq/mmol}$ , Amersham). The plates were then mixed and left to incubate overnight at  $4^{\circ}\text{C}$ .

After at least 15 hours of incubation a dextran and activated charcoal suspension in assay buffer was added to each sample before centrifugation at 3000rpm (1900g) for 15 minutes. Supernatants from the wells were placed into low cross talk 96 well plates (Wallac) with an equal volume of OptiPhase 'SuperMix' liquid scintillant (Wallac Scintillation products.) before counting in a Micrbeta liquid scintillation counter (Wallac Oy, SF-20101 Turku, Finland.). Final concentration values are expressed as nM. Limit of detection of the assay was  $<0.5\text{ nM}$  with an average within assay coefficient of variation of 6% and between assay variation of 15%.



## **5. Statistical Methods**

### **5.1 Time Points in Analysis**

There are several options for examining data with responses at a number of time-points. One approach is to include all the data for all time-points in a single, repeated measures analysis. This option has the advantage that all data points are included together, and so the analyses are based a larger number of observations.

However, there are also disadvantages in that, from an analysis of all data points combined, it is more difficult to identify the comparisons of specific interest (which in the present study was the difference between groups in changes from baseline).

Another difficulty with this method is trying to fit interactions between group factors and other, potentially moderating factors. This is especially problematic if the nature of these interactions is different at different time-points. As Hewett et al. (1992) point out, this method may often fail to directly answer the research question. At best, the consequence is that further testing is needed to establish the significance of the effects of interest, and at worst, this may lead to interesting but conflicting variations within the data across the time-points counter-balancing each other and being obscured.

An additional problem with analysing the four time points together in the present study was that not all potential mediating factors are relevant at all time points. An example is the change between time 1 and time 3 in dependency (CAPE-BRS). To include this factor in an analysis of all time points would not make

sense since this change had not been examined at time 2 and would therefore be irrelevant.

Therefore, it was decided that greater clarity would be achieved by analysing the data via between-groups Analyses of Covariance (ANCOVA) for each time-point separately, using the baseline score on the dependant variable as a covariate in each case. This effectively adjusts the results at each subsequent time-point for the time 1 score, taking account of change in the measure over time. For example, if the outcome was depression at time 2, then depression at time 1 was included as a covariate. This method also allows interactions with treatment group to be targeted specifically to those time-points where differences between groups, and interactions between factors, may vary.

## **5.2 Change Scores**

The aim of present study was not only to examine the effects of respite intervention, but also to investigate the extent to which changes in social activity (from time 1 to 2) and changes in dependency (time 1 to 3) moderated the effect of intervention. It was decided that change would be quantified in the present study by calculating the arithmetic difference between baseline and follow up (known as delta scores). It is acknowledged, however, that there are alternative approaches commonly used to quantify change.

The most common alternative is to calculate residualised change scores, which involves regressing the follow up scores on the baseline scores, calculating a predicted value, and subtracting this predicted score from the observed score. This delta approach has been criticised on the basis that the presumed negative correlation between change and baseline score, which the residualised change

score avoids, may bias findings. It has also been claimed that residualised change scores are inherently more reliable than delta scores.

However, there are important arguments against the residualised approach. First, the assumption that residualised change scores have greater reliability than delta scores has been called into question. Llabre et al (1991) present data to suggest that delta and residualised change are comparable with respect to their ability to generalise across multiple comparisons. They also show that as the correlation between baseline and follow up increases, the reliability of residualised change scores decreases.

This may be a particular problem in the present study, which includes a number of outcomes that are likely to be relatively stable over time and exhibit high test-retest correlations. For example, while the level of physical symptoms reported by participants may vary to some degree over the study period (due to respite intervention or otherwise) higher scores at baseline are still likely to correspond to higher scores at follow up due to the influence of the underlying physical condition, individual differences in the tendency to report symptoms, and age.

Second, as Llabre et al (1991) point out, the variance accounted for in follow up scores by baseline scores, which the residualised change score controls for, will often be 'meaningful variance'. This may be especially true where the aim of a study is to test the efficacy of an intervention in a real life 'externally valid' setting. To artificially remove this variance may be to create a less than 'real world' context for evaluation.

In the present study, for example, if carers with a high depression score at baseline do indeed experience more improvement in their score than carers at a lower level initial level then this reflects the context in which agencies provide respite care and raises important questions about for whom respite may be of most benefit. It was therefore decided to base analyses on the greater clarity and external validity offered by delta change scores in the present study.

### **5.3.1 Type I and Type II Error**

The present study, for the purpose of providing a comprehensive test of the effects of respite, utilised several outcome variables. The consequence of this, however, was inevitably that numerous tests would be required, which in turn, may be argued to increase the chance of making a type I error (ie – finding a significant result by chance).

One option for reducing the chances of a type 1 error is to reduce alpha, and only consider an effect as 'significant' at, for example, the 1% rather than the 5% level. Procedures are available for re-calculating alpha, such as the Bonferroni method, where a modified significant criterion is used based upon the number of statistical tests conducted on the data. A reduction in alpha is made based either on the total number of tests or sequentially as tests are performed.

A serious problem associated with the Bonferroni procedure is a substantial reduction in power and an elevation in the chances of making a type II error (ie - accepting an incorrect null hypothesis) in each test (Jennions and Møller, 2003). According to Nakagawa (2004), in the majority of work in the behavioural sciences, bonferroni corrections leave statistical power unacceptably low. This is particularly the case in studies that are examining potentially small effect sizes,

measuring more than five variables, or are interested in the interactive effect between factors. As all of these were the case in the present study, and it was therefore decided that, rather than making a bonferroni adjustment to say 1% and simply rejecting effects as 'non-significant', all effects found to be significant at the 5% level would be reported.

#### **5.4 Moderating and Mediating Analyses**

As discussed earlier in this chapter, the action of any treatment or intervention may often depend or differ according to certain 'third variables'. The present study is concerned with the extent to which the effect of respite on outcome changes according to two factors: carers' social activity during respite (specifically the change in activity from baseline to time 2), and the dependency exhibited by the care recipient (specifically, the change from baseline to time 3 - as reported by the carer).

Third variables may have either 'moderating' or 'mediating' effects. Baron & Kenny (1986) were of the first writers to highlight the fact that, particularly in the social sciences, these two types of effect are often confused and the terms used interchangeably. However, there are important distinctions to make between the two.

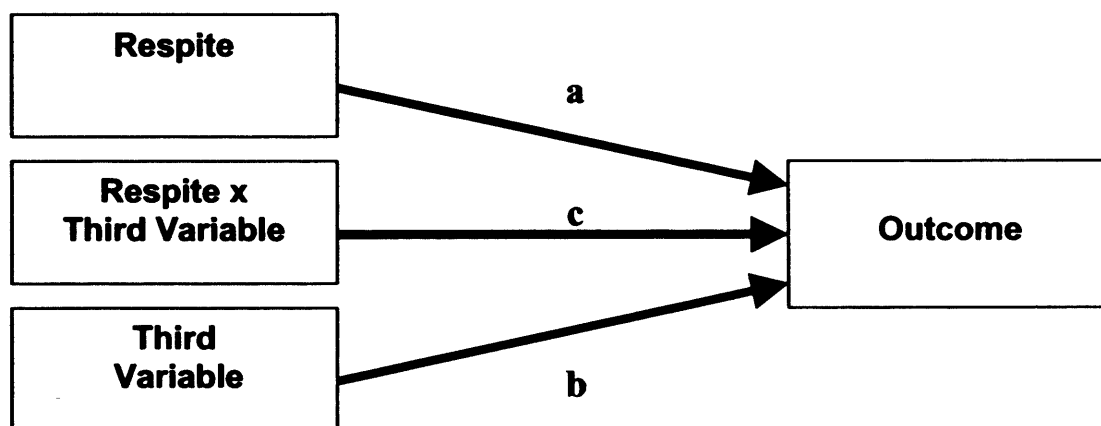
##### **5.4.1 Moderating Effects**

As already discussed, a 'moderator' affects either the direction or strength (or both) of an independent variable on a dependant variable. In relation to intervention or treatment, the intervention will have one effect when a moderator

variable is 'high' or 'present', and a different effect when the moderator is 'low' or 'absent'. In this way, the discovery of moderating variables help us identify the conditions under which an intervention will have its expected effects on outcome. Importantly, the conclusion that a third variable acts as a moderator does not imply that the effects of the intervention 'work through' it. Rather, it is simply an observation about when or in what circumstances an intervention has a certain effect.

In relation to the present study, a moderating effect of the third variables on outcome could be represented as in figure 7.3. There essentially three paths by which outcome (in terms of depression, physical symptoms, carer burden and cortisol) may be affected. First, they may be affected directly by respite (a). Second, they may be affected directly by a third variable (b). And finally, they may also be affected by the interaction or product of the two (c).

**Figure 7.3: Moderating effect of a third variable.**



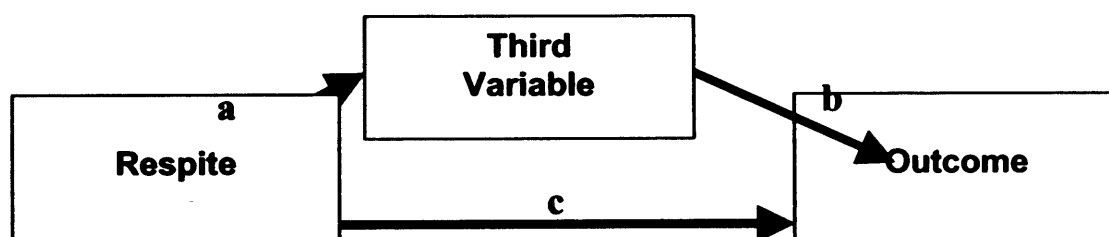
### 5.4.2 Mediating Effects

A third variable may be said to exert a 'mediating' effect if it accounts for the relationship between the predictor and the outcome (Baron & Kenny, 1986). While moderating variables tell us about *when* a certain effect will occur, mediators say more about *how* and *why* the effect occurs. In this way they provide an insight into the mechanism of action.

Unlike a moderator model, mediation usually implies two causal paths feeding into an outcome (see figure 7.4). The first is the direct effect of the independent variable on outcome (c), while the second is the effect of the mediating third variable on outcome (b) (which itself has a causal path leading to it from the independent variable) (a).

In the current study, and in line with recommendations by Baron & Kenny (1986), the criteria for establishing whether or not the third variables in the current study are operating as mediators was defined as follows:

**Figure 7.4: Mediating effect of a third variable.**



First, there must be an effect to mediate, so respite group must be associated with changes in outcome. Second, respite group must be associated with changes in the mediator. Third, the mediator must also predict changes in outcome. And

finally, when the mediator is controlled, any initial association between respite and depression outcome must be significantly reduced or eliminated

## **5.5 Summary of Statistical Procedures**

The first set of statistical analyses conducted was concerned with findings at baseline, and related primarily to the relationships between the variables measured in the study. Following this, and as discussed earlier, it was decided that separate analyses should be conducted for the effects of respite at each of the three follow up assessments. As Baron & Kenny (1986) highlight, in many cases, one may begin with a moderator orientation and then move on to examine mediating effects. They recommend an approach that combines mediation and moderation, which begins with tests for moderation and then goes to test for mediating effects.

This approach was adopted in the present study. Tests for mediation were conducted whether or not the tests for moderation were significant. This is because it is perfectly possible that a mediation effect may exist even where a moderation effect does not.

### **5.5.1 Moderator Analyses**

At each follow-up time point, the first procedure was to examine the effect of respite group on outcome, and the extent to which this effect may differ at different levels of the third variables (ie- changes in social activity and dependency).

In testing for moderation effects, two options present themselves. The first alternative is to attempt to examine moderation effects by using the third variable



in its original, continuous form. While this method may be seen as more straight forward and one that avoids arbitrary divisions of a variable, serious concerns have often been raised in the statistical literature about the low power of this method to detect true interaction effects. Aguinis et al. (2001) showed that, using this approach; the power to detect interaction effects in a typical study is only .20 to .34, and much lower than the recommended level of .80. Furthermore, it has been demonstrated that this issue is a particular problem in non-experimental designs (such as the present study) (McClelland & Judd, 1993).

An alternative method is to examine whether the effect of the independent variables on outcome is different at distinct, pre-determined levels of the third variable. Baron & Kenny (1986) highlight that, in many cases, there is a particular point (or range of points) at which the effect of the independent variable on outcome may be altered (in strength and/or direction). In repeated measures designs, such as in the present study, one such point is likely to be where changes in the moderator variable over time switch from a decrease to an increase or vice versa. In these cases, Baron & Kenny (1986) suggest "dichotomizing the moderator at the point at which the function is presumed to accelerate."

It was decided therefore that, for the purposes of the moderator analyses, participants would be divided up into groups according to whether they reported an increase in the third variable, or a decrease / no change. This arguably represents a meaningful division in conceptual terms, with increases in either social activity or dependency being salient to study participants, particularly over the relatively short time period between assessments in the current study. This method also provides for a more simple and readily interpretable statistical

analysis of moderation. The possibility of dividing the moderator into three groups (decreased, unchanged and increased) was also considered. However, while this may have also been conceptually valid, the likely effect of a 3x2 design (as opposed to a 2x2 design) would have been to lead to small cell sizes (particularly relating to the 'unchanged' level) and seriously reduce statistical power. Since the power calculation for the present study (section 2.3) had revealed that a sample of well over 100 participants was required to demonstrate an effect across two groups, the option adding of more cells to the analysis was rejected.

Baron & Kenny (1986) outline a number of statistical tests for examining the (potential) moderating effect of a third variable. In cases where both the independent variable and the potential moderator are dichotomous, a standard 2 X 2 analysis of covariance (ANCOVA) is appropriate, with the key test for moderation being that the interaction term (independent variable x moderator) is significantly associated with outcome.

In running the tests, both the main effects of respite and the third variables on the outcome variable were examined, as well as the interaction or product between predictor and the moderator. A significant interaction was set as the criteria for concluding a moderating effect, whether or not the main effects were significant (as these are not strictly relevant to demonstrating moderation). Analyses also included age and sex as covariates (so as to control for any effects of these factors).

The method of splitting a continuous distribution into groups does have disadvantages. In particular, if the sample is split then the result may be two sub-samples that are skewed and differ significantly from a normal distribution. It may

also lead to a loss of statistical power. However, it has been demonstrated that ANOVA is robust in the face violations of the assumption of normality, and that the more the groups are similar in size, the more robust ANOVA will be (Jackson and Brashers, 1994).

### **5.5.2 Mediator Analyses**

Unlike when testing for moderation, ANOVA provides a limited test of mediation. In particular, the ANOVA approach unnecessarily restricts variance in comparison to equivalent regression models (Baron & Kenny, 1986). Therefore, in the present study, mediating effects were examined using multiple linear regression. The hierarchical approach enters variables in a series of blocks, thus revealing whether each new block of variables adds anything to the prediction produced by the previous blocks of variables. This method is useful when the intention is to control for the effects of one variable (such as baseline outcome scores) on the prediction. It also allows for the use of dichotomous predictor variables such as respite group.

The 'enter' procedure for variable selection was used. This approach is one in which all variables in a block are entered in a single step. By entering variables in a series of blocks the analysis indicates whether each new block of variables adds anything to the prediction produced by the previous blocks of variables. Baseline levels of outcome were controlled for in each analysis including social activity where appropriate (social activity was entered as a continuous variable). The other variables controlled for were age, sex and the baseline level of dependency (as this differed significantly between the two study groups at baseline).

In each analysis, the amount of variance in the dependant variable accounted for by the independent variables was examined (using the adjusted  $R^2$  statistic, which lowers  $R^2$  as the number of independents, increases). In addition, the regression (b) coefficient was of interest, which represents the average amount the dependent variable increases when the independent variable increases one unit (and other variables are held constant). Since the independent variables were measures in different units, the standardized coefficients (beta) were presented so as to make the regression coefficients more comparable. The standardized coefficients present the results as if the data were transformed to z scores prior to the regression analysis.

In all cases, tests were carried out for multicollinearity. If independent variables are highly intercorrelated then small changes in the data values may lead to large changes in the estimates of the coefficients. Condition indices were examined for the full model (a condition index is the square root of the ratio of the largest eigenvalue to each successive eigenvalue). Condition indices are used to flag excessive collinearity in the data. A condition index over 30 suggests serious collinearity problems and an index over 15 indicates possible collinearity problems. In no case was the condition index over 15, indicating an acceptable degree of collinearity.

## **Chapter 8: Baseline Results**

- 1. Sample Size and attrition**
- 2. Group Comparisons: Participant Characteristics**
- 3. Group Comparisons: Outcome Measures**
- 4. Interrelationships between outcome measures and third variables**
- 5. Predictors of carers' psychological well-being at baseline**
- 6. Properties of new measures**
- 7. Summary**

## **1. Sample size and attrition**

Data were collected from a total of 112 participants at baseline (57 controls and 55 in the respite group). At time four, 89 participants remained in the study (45 controls and 44 in the respite group).

Non-completion of the study was at similar levels in both groups. Non completion was due to either the care recipient leaving home for long-term care, the death of the care recipient, carer illness, an unwillingness of the carer to complete the study, or because the care recipient went into hospital during the study. Table 8.1 illustrates the number of participants remaining in the study at each time point by study group.

**Table 8.1: Participants remaining in the study at each time point by study group**

	<b>time 1</b>	<b>time 2</b>	<b>time 3</b>	<b>time 4</b>
<b>Control</b>	57	55	52	45
<b>respite</b>	55	45	51	44
<b>total</b>	112	100	103	89

A power calculation revealed that the final sample size of n=89 may have left the study somewhat underpowered. This sample size would not have been sufficient to detect a difference any less than 5 points in CES-D scores between groups at time 4 (based on the mean CES-D score of 16 and standard deviation of 9.5 found at baseline – see below).

Independent samples t-tests were performed in order to examine differences on baseline measures between those participants completing the study and those dropping out. No significant differences emerged. At time two (during respite), several respite group participants (n=8) were unavailable for interview due to the fact that they had used their respite break to travel away from home. These participants remained in the study and provided data at subsequent follow-up assessments. Once again, t-tests revealed no differences between these eight participants and the rest of the sample on baseline assessments.

## **2. Group Comparisons: Participant Characteristics**

The participants were all full-time carers for a spouse or partner. The carers had a mean age of 67.77 years and 64% were female. Carers from ethnic minorities were under-represented in the study, with 92% of the sample being white. Four participants were Indian and one participant came from each of the Black African, Black Other and Asian Other groups. Two participants did not state an ethnic background.

All care recipients (mean age = of 69.13 years) lived on a full-time basis with their carer, and had been diagnosed with a range of conditions. Approximately a third (32%) of participants were caring for someone with dementia, while just over a quarter (27%) were caring for their spouse after a stroke and 15% were caring for someone with multiple sclerosis.

The rest of the sample was made up of carers looking after spouses with a range of other conditions (examples of which were motor neurone disease, AIDS, and

Rheumatoid Arthritis). In a large proportion of cases, multiple conditions were reported rather than one single diagnosis.

While the carer age, sex, care recipient age and the duration of the care-recipients' illness were similar across both of the study groups, chi squared tests revealed that the proportion of carers looking after someone with dementia was greater in the respite group (see tables 8.2 and 8.3).

**Table 8.2: Participant Characteristics by Group**

Variable	Control Mean (SD)	Respite Mean (SD)	Difference in Means	95% CI of Difference		p
				Lower	Upper	
Age	68.47	64.96	3.51	-0.83	7.85	.11
Age of Care Recipient	71.70	67.20	4.49	-0.71	9.69	.09
Illness duration (months)	156.50	155.77	0.73	-62.96	64.43	.98

**Table 8.3: Sex and Dementia Status by Group**

Variable	Category	Control N (%)	Respite N (%)	p
Sex	Female	38 (67%)	34 (62%)	0.59
	Male	19 (33%)	21 (38%)	
Dementia	Yes	13 (25%)	25 (47%)	0.02
	No	40 (75%)	28 (53%)	



The respite group participants reported a mean number of 9.02 days (std = 3.20) of residential respite care during the study period (during which assessment time 2 was conducted). There was no correlation found between the length of respite and either baseline outcomes or changes in outcomes across the study period.

Other forms of support came in the form of regular in-home care and day centre care. Table 8.4 shows, by study group, the number carers in receipt of each form (and the percentage of each study group that the number represents).

**Table 8.4: Regular Day Care and Home Based Care by Group**

	<b>Control N (%)</b>	<b>Respite N (%)</b>
<b>Home Care</b>	26 (46%)	29 (53%)
<b>Day Care</b>	18 (32%)	32 (58%)

Chi – Squared tests indicated that the number of carers in regular receipt of in-home care was similar across the study groups (which remained the case across the study period). The number of carers in receipt of day care, however, was significantly higher among the respite group ( $\text{Chi}^2 = 9.37$ ,  $p < 0.01$ ), a difference that again remained stable across the study period. The number of carers in the respite group in receipt of day care was almost double that observed among the control group.

As the numbers of carers in receipt of day care was consistently and significantly different between the two study groups, it was decided that the association of day care receipt with outcome variables should also be explicitly examined in the

follow up analyses rather than just at baseline. The exception was time 2 (during respite) at which day care among the respite care group was not relevant due to the absence of the care recipient. These analyses are presented in the relevant, subsequent results chapters.

### 3. Group Comparisons: Outcome Measures

All outcome and third variable distributions were examined with box-plots. Values were deleted if they were more than 3 box lengths from the upper or lower edge of the box (box length = inter-quartile range). Histograms were then examined and all distributions were found to be normal (skewness levels between +2 and -2).

The mean scores at baseline (by group) on each of the outcome and third variables are presented in table 9.5. Independent samples t-tests were carried out in order to examine group differences. The groups were compared in terms of the outcome variables as well as social activity and care recipient dependency.

**Table 8.5: Group comparisons at baseline**

Variable	Control Mean	Respite Mean	Mean Difference	95% CI of Difference	
				Lower	Upper
Depression	16.43	15.38	1.05	-2.58	4.68
Symptoms	7.49	6.45	1.04	-0.54	2.61
Objective Burden	18.24	19.80	-1.57	-2.76	-0.37
Subjective Stress	13.46	13.20	0.27	-0.43	0.97
Subjective Demand	12.11	12.14	-0.03	-0.54	0.48
Cortisol – 10 am	9.74	8.92	0.82	-1.75	3.39

Cortisol – 2 pm	6.55	8.11	-1.55	-3.51	0.40
Cortisol – 6 pm	3.81	4.97	-1.15	-2.30	0.00
Cortisol – 10 pm	2.67	2.62	0.05	-0.59	0.69
Dependency *	15.02	17.81	-2.79	-4.59	-0.99
Social Activity	10.91	12.79	-1.88	-4.27	0.52

\*  $p < 0.01$

Only the difference in dependency was significant, with the respite group reporting a level of dependency almost 3 units and 20% higher than in the control group ( $t=3.07$ ,  $df=110$ ,  $p<0.01$ ).

A multiple regression analysis was performed to examine how much of the excess dependency reported by the respite group could be explained by the larger proportion of dementia diagnoses in this group. With baseline dependency as the dependant variable, diagnosis type was entered into the regression equation first, followed by the study group variable. The results revealed that, together, the two variables explained 22% of the variance in dependency, with the majority of this variance (19%) explained by diagnosis type ( $\beta = -0.44$ ,  $p<0.001$ ). However, study group did still account for 3% of the variance in dependency after illness type was controlled ( $\beta = 0.21$ ,  $p<0.05$ ) (see table 8.6).

**Table 8.6: Model Summary: Predictors of baseline dependency**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
dementia status	.435 <sup>a</sup>	.189	.181	4.54885	.189	23.980	.000
respite group	.481 <sup>b</sup>	.232	.216	4.44919	.043	5.666	.019

#### 4 Interrelationships between outcome measures and third variables

A further set of analyses examined the relationship between all the main outcome measures. The strength of association between each pair of variables was assessed (see table 8.7). The figures reported are the correlation coefficients, together with the associated p-values.

The results indicated that there were significant positive correlations between all of the self-report outcome measures, with the exception of that between subjective demand and objective burden. A particularly strong correlation was found between depression and physical symptoms, with symptoms explaining 36% of the variance in depression levels ( $\beta=0.60$ ,  $p<0.001$ ).

**Table 8.7: Relationship between outcome variables**

	depression	symptoms	objective burden	subjective demand	subjective stress	dependency	social activity
depression	-	0.60**	0.31**	0.26**	0.55**	0.24*	-0.19
symptoms	-	-	0.27**	0.19*	0.35**	0.13	-0.04
objective burden	-	-	-	0.11	0.35**	0.10	-0.02
subjective demand	-	-	-	-	0.20*	-0.08	-0.04
subjective stress	-	-	-	-	-	0.06	-0.05
dependency	-	-	-	-	-	-	-0.03

\*\*  $p<0.01$  \* $p<0.05$

While all of the carer burden variables were positively correlated with depression, subsequent regression analyses revealed that only the subjective stress subscale

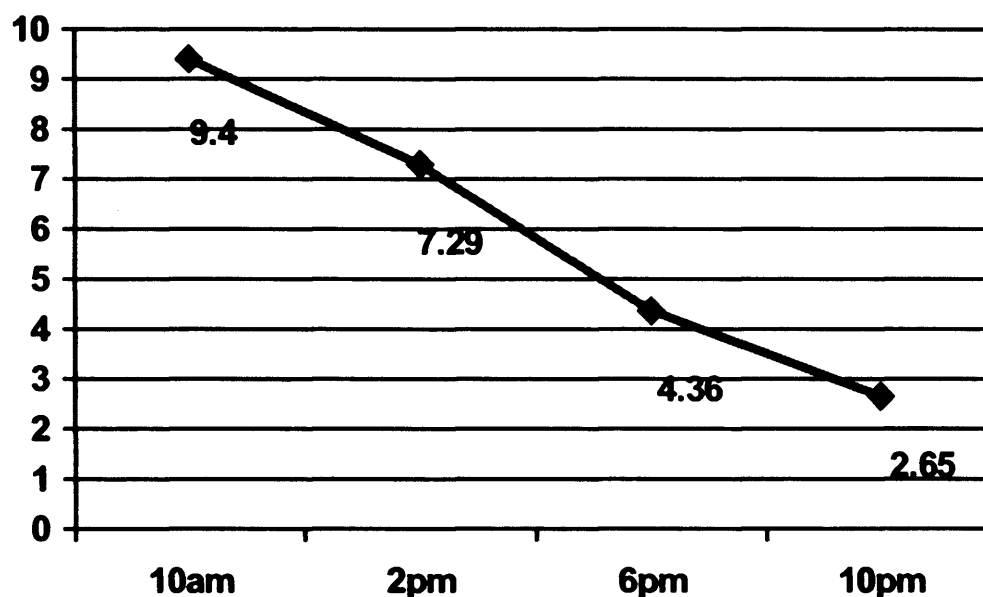
was a significant predictor, explaining 20% of the variance in baseline depression levels ( $\beta=0.48$ ,  $P<0.001$ ).

Social activity was not related to any of the outcome measures, while dependency was only correlated with depression. Regression analysis revealed that scores on the depression measure at baseline accounted for less than 5% of the variance in ratings of dependency at the same time point. This suggests only a minimal amount of overlap between the constructs and that carers' ratings of care recipient dependency were not simply a reflection of their own psychological state.

The findings also revealed that none of the self-report measures were correlated with any of the cortisol outcomes (ie- 10am, 2pm, 6pm and 10pm). Correlation coefficients ranged from  $-0.18$  to  $0.15$  and did not reach significance. Cortisol levels decreased with time of day (see figure 8.8 for the mean levels of cortisol across the sampling day by time point).

The mean difference between the 10 am sample and the 10 pm sample was  $6.04$  ( $\text{std} = 4.77$ ) nmol/l. As was the case for the other cortisol outcomes, the difference between 10 am and 10 pm cortisol was unrelated to any of the self-report outcomes. Neither was it associated with study group or diagnosis type. While the 10am, 2pm, 6pm and 10pm levels were all positively interrelated, the 10 am to 10pm difference was related only to the first two sample variables (table 8.9). Regression analysis revealed that the 10 am sample accounted for 24% of the variance in the 10 am to 10pm difference variable after all the other sample levels had been controlled ( $\beta = 0.55$ ,  $p<0.01$ ).

**Figure 8.8: Mean cortisol levels at baseline (by sampling time) (nmol/l)**



**Table 8.9: Relationships between cortisol outcomes**

	10am	2pm	6pm	10pm	10am-10pm
10am	-	0.62**	0.38**	0.32**	0.96**
2pm	-	-	0.36**	0.34**	0.48**
6pm	-	-	-	0.41**	0.15
10pm	-	-	-	-	0.03
10am-10pm	-	-	-	-	-

\*\* p<0.01

## **5. Predictors of carers' psychological well-being at baseline**

In order to examine which participant characteristics were associated with carers' psychological well-being at baseline, multiple linear regression analysis was used with potential predictors entered in a series of blocks. Variables were chosen for inclusion in the analysis if they either represented a fundamental demographic factor, a characteristic of the objective demands upon the carer or another form of respite other than residential care.

With outcome as the dependent variable, a regression equation was constructed using the age of the carer, sex of carer, level of care recipient dependency, care recipient diagnosis (dementia vs no dementia) and finally, the receipt of regular home care and day care. The results of the analysis are summarized below in table 8.10.

**Table 8.10: Model Summary: Predictors of Baseline Depressive Symptoms**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
age	.025 <sup>a</sup>	.001	-.009	9.83385	.001	.063	.802
sex	.327 <sup>b</sup>	.107	.089	9.34385	.106	11.655	.001
dependency	.395 <sup>c</sup>	.156	.130	9.13188	.049	5.602	.020
dementia	.396 <sup>d</sup>	.157	.122	9.17212	.001	.151	.699
day care	.407 <sup>e</sup>	.166	.122	9.17307	.009	.980	.325
home care	.470 <sup>f</sup>	.221	.171	8.90935	.056	6.707	.011

Three variables emerged as significant predictors of depression. First, the analysis revealed that sex accounted for 10% of the variance in outcome, with women exhibiting higher levels of depression (beta = - 0.33,  $p < 0.001$ ).

Second, after controlling for age and sex, the level of dependency was also positively associated with depression (beta = 0.22,  $p < 0.05$ ) and explained an additional 5% of the variance in outcome. Although caring for a spouse with dementia was associated with a higher level of behavioural problems ( $t = 4.90$ ,  $p < 0.001$ ), a dementia diagnosis did not predict depression after dependency was controlled.

Finally, after controlling for these variables, as well as receipt of day care, regular receipt of home care was still associated with a lower level of depression (beta = - 0.24,  $p < 0.05$ ), explaining an additional 6% of the variance in outcome.

In order to further explore the higher level of depression reported by women, comparisons were made between men and women on the age, diagnosis and illness duration of their care recipient, as well as the reported level of dependency, objective burden and in home / day care support provided (see table 8.11 and 8.12).

T-tests and Chi-Squared tests indicated that men and women did not differ in relation to any of these variables, and re-running the regression analysis with the sex variable entered into the equation at the final step showed that the sex of carer was still a significant predictor of depression even after all the care recipient variables had been controlled (beta = -0.37,  $P < 0.01$ ).

**Table 8.11: Comparisons by sex at baseline (continuous variables)**

Variable	Female	Male	Mean Difference	95% CI of Difference		P (t-test)
				Lower	Upper	
Care Recipient Age	69.60	68.16	1.44	-4.16	7.04	0.61
Illness Duration (mnths)	159.07	150.68	8.40	-58.38	75.18	0.80
Dependency	16.72	15.76	0.96	-1.01	2.92	0.34
Objective Burden	19.24	18.50	0.74	-0.55	2.43	0.26



**Table 8.12: Comparisons by sex at baseline (categorical variables)**

	<b>Female n (%)</b>	<b>Male n (%)</b>	<b>P (chi squared)</b>
<b>Diagnosis of Dementia</b>	23 (33%)	15 (41%)	0.46
<b>Regular In Home Care</b>	37 (52%)	18 (49%)	0.73
<b>Regular Day Care</b>	36 (51%)	14 (38%)	0.20

## **6 Properties of new measures**

In the present study, the Caregiver Burden Scale was adapted to allow carers to indicate a perception of change from a 'normal' level. That is, instead of rating their level of burden in the original absolute sense (eg- 'not at all' to 'a great deal') carers were asked to rate their burden (in the last week) as to whether it had been 'a lot less than usual' to 'a lot more than usual'. Scores for the subscales were positively related to scores on the original instrument ( $r$  ranged from 0.31 to 0.34,  $p < 0.01$ ).

The sub-scales showed moderate internal reliability, with  $\alpha = 0.75$  (objective burden), 0.70 (subjective demand) and 0.63 (subjective stress). Test-retest correlations for the subscales (comparing time 1 and time 4) were 0.49 (objective burden), 0.27 (subjective demand) and 0.44 (subjective stress). These test-retest correlations did not improve when respite group participants were excluded. It was decided to include the subjective demand sub-scale in further analyses although findings were interpreted with caution due to its poor external reliability.

As no standardized tools for assessing social activity were identified, the research team developed a 12-item checklist of social events. The checklist asked participants to estimate the number of times they had engaged in each activity listed in the last seven days. The scale as a whole had a Chronbach's alpha of 0.50, and a test-retest correlation of 0.64 (from time 1 to time 4). The tests revealed that the internal reliability of the scale would not have improved with the removal of any one item.

## **7. Summary**

Approximately two thirds of the sample were women, who were evenly represented across the two study groups. One third of the sample was caring for a spouse or partner with a diagnosis of dementia, significantly more of whom were found in the respite care study group. The respite group participants received, on average, just over 9 days of residential respite care support. Other forms of respite support received during the study period included in-home care (accessed evenly by both study groups throughout the study period) and day care (more likely to be accessed by the respite group participants).

The study groups were found at baseline to have similar ratings on most of the outcome measures. An exception to this was the level of care recipients' dependency, which the respite group rated higher. Further analysis revealed that this was largely (although not completely) explained by the fact that there was a higher proportion of dementia diagnoses reported in the respite group.

In relation to the association between outcome measures, most of the self-report variables (including social activity and dependency) were significantly and positively correlated. This was particularly true for the association between

depression and physical symptoms, suggesting the existence of an underlying factor governing responses. Only the subjective stress subscale of carer burden emerged as a significant predictor of depression.

Carers' ratings of social activity were unrelated to any other self-report variable. Care recipients' dependency was also largely unrelated to ratings of outcome at the same time point. Only depression showed a moderately positive correlation with dependency ratings, although analyses revealed that less than 5% of the variance was shared between the two variables. Dependency was the only variable to differ between the two study groups and to be related to outcome.

None of the self-report measures were related to salivary cortisol as assessed at any of the four sampling times. Cortisol outcomes were, however, significantly and positively interrelated. Time 1 cortisol (10am) explained the vast majority of the variance in the differences observed between morning and evening (10pm) cortisol levels. Cortisol levels at each time point decreased steadily across the day.

Sex of carer, dependency and regular receipt of home care all emerged as significant predictors of depression levels at baseline. There was a significantly higher level of depression among female carers, although they did not differ from male carers in relation to age, care recipient diagnosis, care recipient illness duration, care recipient dependency, objective carer burden or receipt of in home and day care support.

## **Chapter 9: Time 2 Results**

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### **2. Increased versus Unchanged or Decreased Social Activity**

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### **5. Summary**

## **1. Introduction**

The purpose of the time 2 analyses was to examine the effect of study group (respite versus no respite) on outcomes at the mid-point of the respite intervention (or the equivalent time point for controls). In addition, the aim was to examine the conditions under which this effect is either moderated and/or mediated by changes in social activity from baseline to time 2. Change in the other third variable, dependency, would not yet have been fully evident to carers at this time point so it was not included at this stage.

As discussed in the methods section, Baron & Kenny (1986) recommend an approach to the examination of the role of third variables that begins with tests for moderation (using a 2x2 design) and then goes on to examine mediating effects. This approach was adopted in the present study.

## **2 Increased versus Unchanged or Decreased Social Activity**

Changes in social activity from baseline to time 2 were found to vary widely across the sample. Changes were normally distributed around a mean (and median) increase of 1 unit (95% CI = -9.00 to 14.00). The correlation between social activity at times 1 and 2 was 0.57T, demonstrating an acceptable level of test-retest reliability that is high enough to be reliable yet still sensitive to change. The number of days taken into consideration by carers when reporting social activity was not significantly related to their overall score on the measure.

Two groups were created to represent a) those carers reporting an increase in positive social activity from before to during respite, and b) those reporting no change or a decrease in social activity (see section 5.4.2 in the Methods chapter

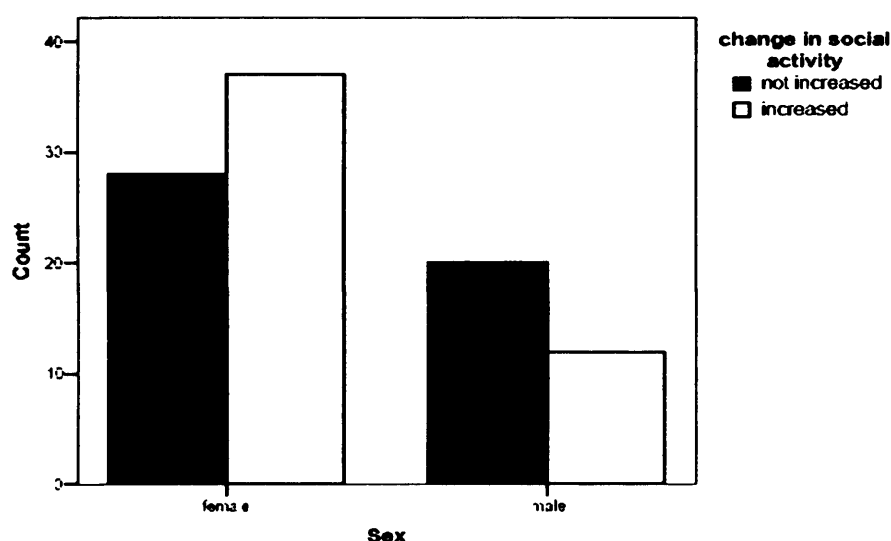
for a justification of this approach). The two groups contained a similar number of participants (see table 10.1), which according to Baron & Kenny (1986) allows maximum statistical power to be derived in ANOVA based moderation analyses. The difference between the two groups on the continuous measure of change on social activity was significant ( $F=151.28$ ,  $df=1,97$ ,  $p<0.001$ ).

**Table 9.1: Changes in social activity from before to during respite**

	N	Mean	Std. Deviation	95% CI	
				Lower	Upper
not increased	48	-4.1042	3.52643	-5.1281	-3.0802
increased	49	6.0000	4.49537	4.7088	7.2912

The 'increased' and 'not increased' groups did not differ in relation to age, diagnosis of care recipient, baseline level of dependency or respite group allocation. A significant effect of sex was revealed however, with a greater proportion of women reporting an increase in social activity than men ( $\chi^2 = 3.23$ ,  $df=1$ ,  $p<0.05$ ). While 57% of the female carers reported an increase in activity, only 38% of the male carers reported an increase (see figure 10.2).

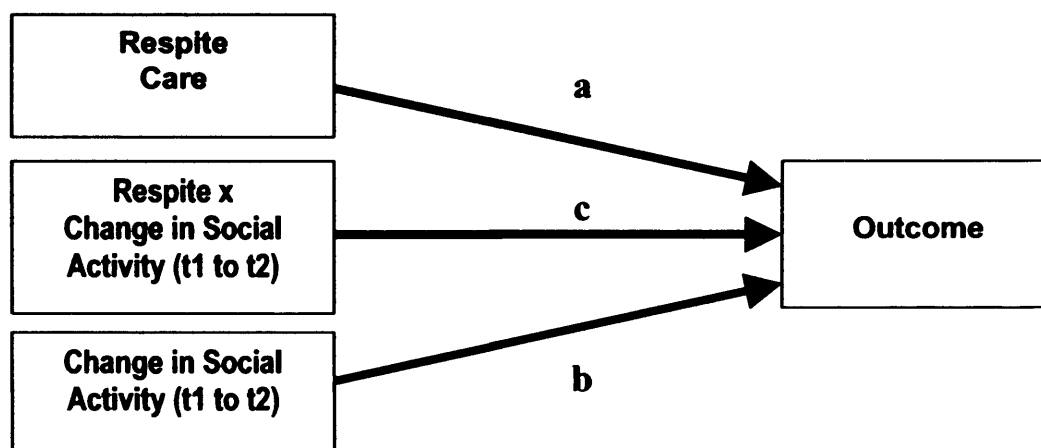
**Figure 9.2: Proportion of male and female carers reporting an increase in social activity**



### 3 Tests of Direct and Moderating Effects

In addition to the overall effect of group on outcome, the interaction between group and change in positive social activity from baseline to time 2 was entered into the analysis. Of interest was whether the effect of group on outcome varied on that factor (see figure 9.3).

**Figure 9.3: Direct and moderating effects tested at Time 2 (during respite)**



Two-way (2x2) Analyses of Covariance were performed to investigate the effect of respite group allocation on outcomes, and whether this effect differed for those reporting increases or no increases in social activity. In each analysis, the dependant variable was the measured outcome at time 2, with outcome measures at baseline controlled for as covariates.

Age and sex were also entered into the analyses as covariates, as was the baseline level of care recipient dependency. This latter variable was controlled because it was the one variable found at baseline to be both significantly associated with outcome and also to be significantly different between the study groups.

As mentioned in the previous chapter the numbers of carers in receipt of day care was consistently and significantly different between the two study groups. Hence, it was decided that the association of day care receipt with outcome variables should also be explicitly examined in the follow up analyses.

Independent t-tests were performed to compare the time 3 mean scores on outcomes of those carers reporting receipt of day care in the previous week and those not reporting any day care. No significant differences were found.

### 3.1 Depression

Table 9.4 compares the mean levels of depression at time 2 (baseline adjusted) between the two study groups and between those reporting and not reporting an increase in social activity. Estimated marginal means are presented that are adjusted for the effects of covariates (including baseline scores on the outcome measure).

**Table 9.4: Depression at time 2 (baseline adjusted) by study group and change in social activity**

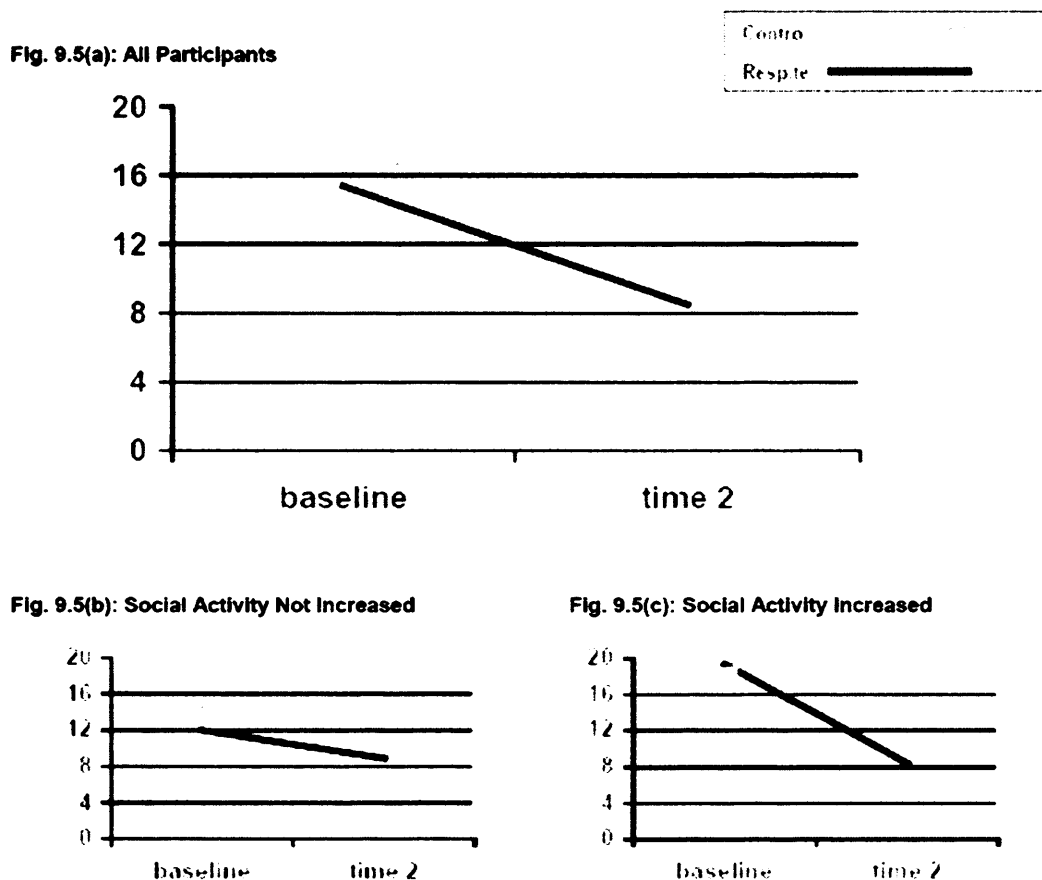
group	change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	16.274	1.207	13.876	18.672
	increased	18.590	1.288	16.031	21.150
respite	not increased	11.327	1.506	8.332	14.321
	increased	6.853	1.441	3.990	9.717

Analyses revealed a significant main effect of respite group ( $F=33.86$ ,  $df=1,96$ ,  $p<0.001$ ), with those receiving respite exhibiting lower levels of depression at time 2 in comparison to controls (see figure 9.5a).



The results also indicated that the effect of respite differed according to whether or not social activity had increased from baseline ( $F=6.31$ ,  $df=1,95$ ,  $p<0.05$ ). In the group reporting no increase in activity the effect of respite was diminished in comparison to the effect among those reporting an increase (see figures 9.5b and 9.5c).

**Figure 9.5: Effects of respite on depression**



### 3.2 Physical Symptoms

Table 9.6 compares physical symptoms at time 2 (baseline adjusted) between the two study groups and between those reporting increases or no increases / decreases in social activity. Again, analysis of covariance revealed a significant main effect of group on physical symptoms at time 2 ( $F=21.5$ ,  $df=1,96$ ,  $p<0.001$ ).

As with the effect on depression, those receiving respite exhibited lower levels of symptoms at time 2 in comparison to controls (see figure 9.7a).

ANCOVA also revealed that the effect of respite differed again according to whether or not social activity had increased from baseline ( $F=4.13$ ,  $df=1,95$ ,  $p<0.05$ ). In the group reporting no increase in activity the effect of respite was diminished in comparison to the effect among those reporting an increase.

Table 9.6: Symptoms at time 2 (baseline adjusted) by study group and change in social activity

group	change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	6.480 <sup>a</sup>	.518	5.452	7.508
	increased	8.048 <sup>a</sup>	.562	6.931	9.165
respite	not increased	4.849 <sup>a</sup>	.637	3.584	6.114
	increased	4.101 <sup>a</sup>	.600	2.909	5.293

Figure 9.7. Effects of respite on physical outcomes

Figure 9.7 (a): All Participants

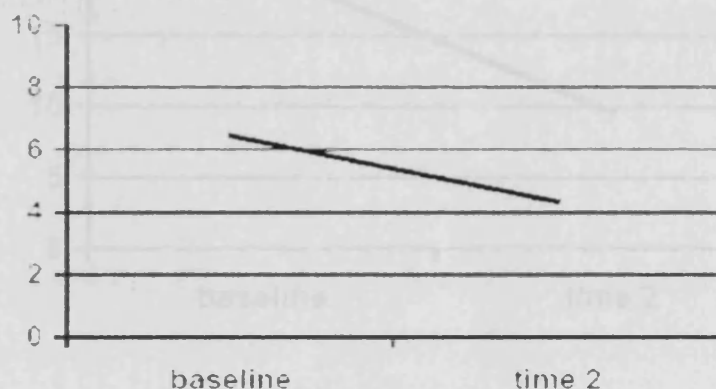


Figure 9.7 (b): Social Activity Not Increased

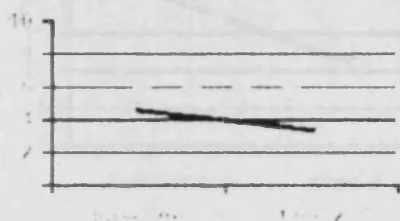
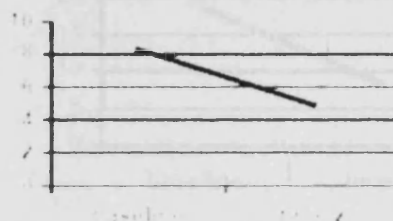


Figure 9.7 (c): Social Activity Increased



### 3.3 Objective Carer Burden

Table 9.8 compares objective burden at time 2 (baseline adjusted) between the two study groups and between those reporting and not reporting an increase in social activity.

Table 9.8: Objective Burden at time 2 by study group and change in social activity

group	change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	17.764 <sup>a</sup>	.539	16.691	18.836
	increased	19.602 <sup>a</sup>	.575	18.459	20.745
respite	not increased	10.572 <sup>a</sup>	.688	9.204	11.940
	increased	8.449 <sup>a</sup>	.627	7.203	9.695

Figure 9.9: Effects of respite on objective burden

Figure 9.9(a): All Participants

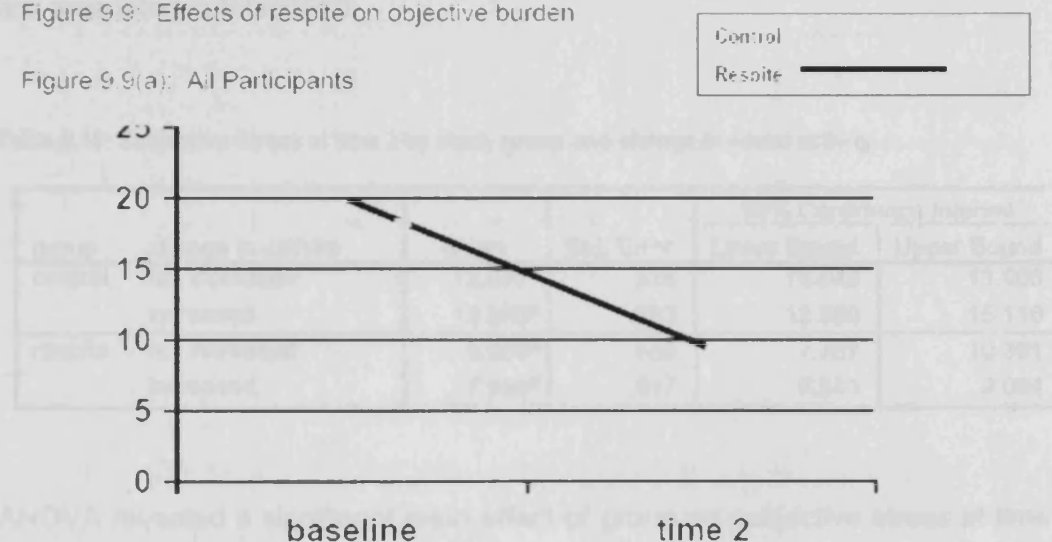


Figure 9.9(b): Social Activity Not Increased

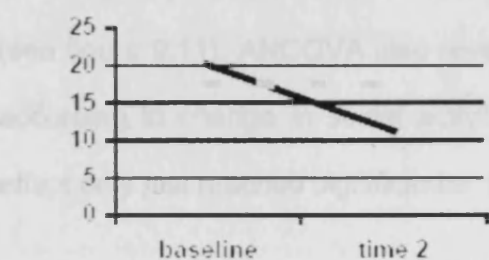
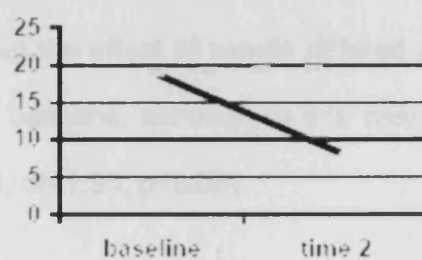


Figure 9.9(c): Social Activity Increased



Again, ANOVA revealed a significant main effect of group on objective burden at time 2 ( $F=203.29$ ,  $df=1,96$ ,  $p<0.001$ ). As with the effect on the previous two outcomes, those receiving respite reported lower levels of burden at time 2 in comparison to controls (see figure 9.9). Also consistent with the previous outcomes was that the effect of respite differed according to change in social activity from baseline ( $F=10.29$ ,  $df=1,95$ ,  $p<0.01$ ). As before, the effect of respite was somewhat larger in the group that increased their social activity.

### 3.4 Subjective Carer Stress

The levels of subjective stress at time 2 (baseline adjusted) between the two study groups and between those increasing and not increasing their social activity are presented in table 9.10.

**Table 9.10: Subjective Stress at time 2 by study group and change in social activity**

group	change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	12.877 <sup>a</sup>	.518	11.848	13.906
	increased	13.990 <sup>a</sup>	.563	12.869	15.110
respite	not increased	9.089 <sup>a</sup>	.655	7.787	10.391
	increased	7.868 <sup>a</sup>	.617	6.641	9.094

ANOVA revealed a significant main effect of group on subjective stress at time 2 ( $F=63.42$ ,  $df=1,96$ ,  $p<0.001$ ). As with the effect on the previous outcomes, those receiving respite reported lower levels of stress at time 2 in comparison to controls (see figure 9.11). ANCOVA also revealed that the effect of respite differed again according to change in social activity from baseline, although in this case, the effect only just reached significance ( $F=3.98$ ,  $df=1,95$ ,  $p<0.05$ ).

Figure 9.11: Effects of respite on subjective stress

Figure 9.11(a): All Participants

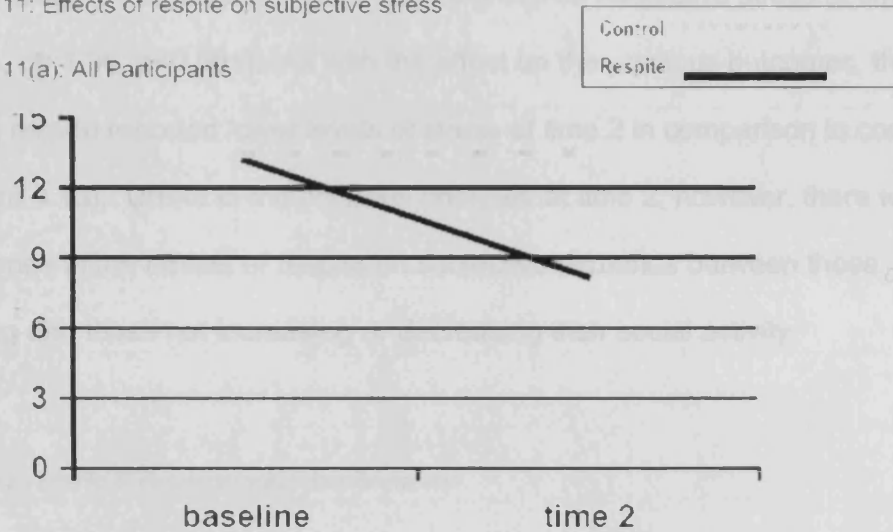


Figure 9.11(b): Social Activity Not Increased

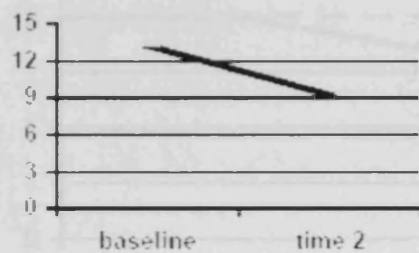
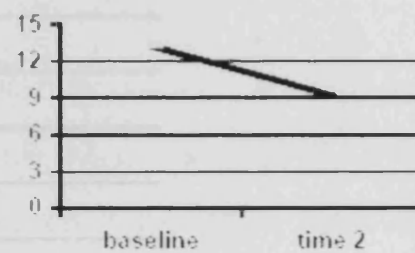


Figure 9.11(c): Social Activity Increased



### 3.5 Subjective Demand

Table 9.12 compares the mean levels of subjective demands at time 2 (baseline adjusted) between the two study groups and between those reporting and not reporting an increase in social activity.

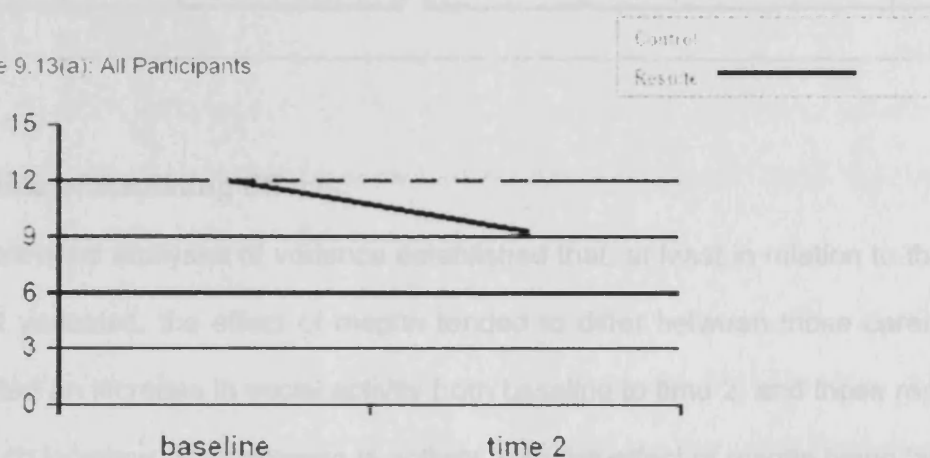
Table 9.12: Depression at time 2 (baseline adjusted) by study group and change in social activity

group	change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	12.042 <sup>a</sup>	.409	11.227	12.856
	increased	12.149 <sup>a</sup>	.448	11.259	13.039
respite	not increased	10.138 <sup>a</sup>	.519	9.105	11.170
	increased	9.126 <sup>a</sup>	.492	8.148	10.105

ANOVA revealed a significant main effect of group on subjective stress at time 2 ( $F=24.93$ ,  $df=1,96$ ,  $p<0.001$ ). As with the effect on the previous outcomes, those receiving respite reported lower levels of stress at time 2 in comparison to controls (see figure 9.13). Unlike in the previous analyses at time 2, however, there was no difference in the effects of respite on subjective demands between those increasing and those not increasing or decreasing their social activity.

Figure 9.13: Effects of respite on subjective demands

Figure 9.13(a): All Participants



### 3.6 Cortisol

Cortisol was examined by time of day point so as to allow the identification of any different effects at each sampling point. Table 9.14 presents the change from baseline to time 2 in cortisol levels by group for 10 am, 2pm, 6pm and 10pm samples. In contrast to the findings for the self-report variables, analyses of covariance did not reveal any significant effect of respite group on cortisol at any sampling time. In addition, there was no effect of change in social activity (either directly or with study group) on cortisol levels at any sampling time.

**Table 9.14: Cortisol at baseline and time 2 by group (spit by sampling time)**

10 am					2pm				
	control		respite			control		respite	
	Mean	Std	Mean	Std		Mean	Std	Mean	Std
baseline	9.74	6.30	8.92	6.00	baseline	6.55	4.71	8.11	4.89
time 2	9.98	6.11	10.00	6.61	time 2	5.87	4.07	7.43	5.37

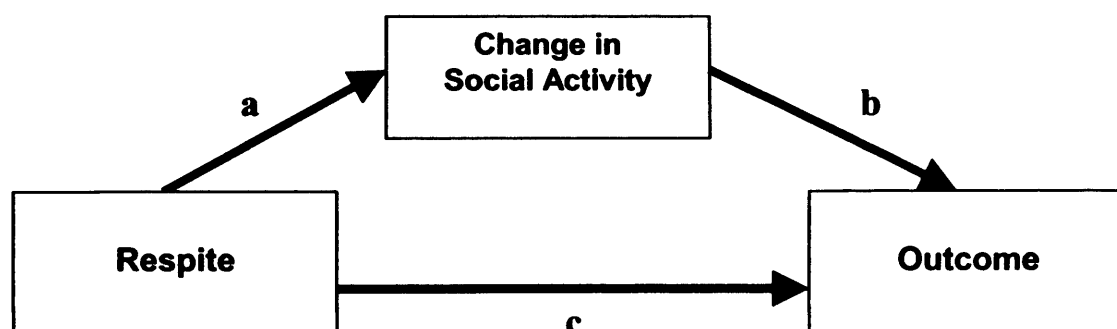
  

6 pm					10 pm				
	control		respite			control		respite	
	Mean	Std	Mean	Std		Mean	Std	Mean	Std
baseline	3.81	2.60	4.97	3.21	baseline	2.67	1.49	2.62	1.48
time 2	3.42	2.14	4.19	2.38	time 2	3.04	2.20	3.67	2.33

#### 4. Tests of Mediating Effects

The previous analyses of variance established that, at least in relation to the self-report variables, the effect of respite tended to differ between those carers who reported an increase in social activity from baseline to time 2, and those reporting no such increase or a decrease in activity (with the effect of respite being larger in the former case). While this implies that changes in social activity may moderate the effect of respite, it does not suggest that respite 'works through' social activity and is 'mediated' by it.

**Figure 9.15: Mediating effects at time 2**



As discussed in the methods chapter, the criteria for establishing whether or not the third variables are operating as mediators was defined as follows: First, there must be an effect to mediate, so respite group must be associated with changes in outcome. Second, respite group must be associated with changes in the mediator. Third, the mediator must also predict changes in outcome. If these paths are found, the final test for mediation is to examine whether, when the mediator is controlled, any initial association between respite and depression outcome is significantly reduced or eliminated.

Since ANOVA provides a limited test of mediation, mediating effects were examined using multiple linear regression ('enter' method) (see the Methods chapter for justification of this approach).

For purposes of clarity, each step in the analyses for the first outcome (depression) is illustrated using a diagram showing exactly which relationships in the model were tested. For analyses of subsequent outcomes, no such diagrams will be used and tables reporting the results of regression analyses will only be included in cases when significant findings were revealed.

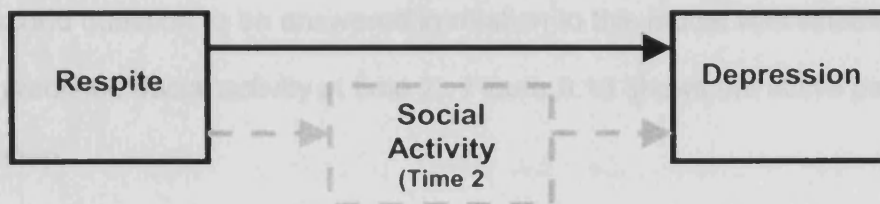
Variables were selected for entry into the regression analyses if they a) functioned as a baseline variable (eg – time 1 depression or time 1 social activity), represented a fundamental demographic (age and sex), or an independent (predictor) variable (ie – respite, no respite). The only other criteria for entry into the equation were if a variable both differed significantly between the study groups and was related to outcome. The only variable meeting this criteria was baseline levels of dependency (labelled as 'disturbance' in the results tables).



## 4.1 Depression

The first question to be answered in relation to depression was whether respite group predicted depression at time 2. Figure 9.16 shows the active path tested in this step (solid black lines) and the paths not tested (broken grey lines).

Figure 9.16: Effect of respite on depression



The results of the multiple regression analysis revealed that, taken together, the variables significantly predicted depression at time 2, ( $F^{(5,95)} = 23.80, p < 0.001$ ).

The total adjusted  $R$  squared value indicated that 55% of the variance in depression was explained by the model, and that respite group accounted for 18% of the variance after the other variables had been controlled (see table 9.17 for summary of the model). The beta coefficient indicated a lower depression level in the respite group ( $\beta = -0.47, p < 0.001$ ).

Table 9.17: Model Summary: Effect of Respite on Social Activity

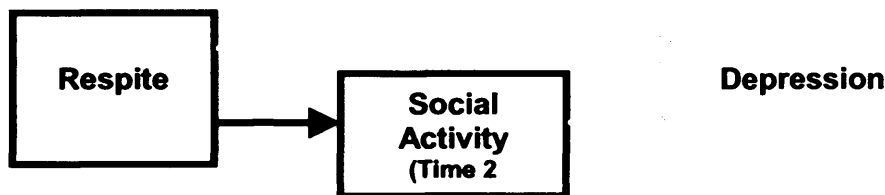
Model	R <sup>2</sup>	F	Sig.	Adjusted R <sup>2</sup>	Delta R <sup>2</sup>	Change Statistics	
						F	Sig.
1. Constant	.000	1.000	.954	-.000	.000	1.000	.954
2. Respite group	.180	3.200	.078	.154	.180	3.200	.078

**Table 9.17: Model Summary: Effect of respite on depression**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline depression	.588 <sup>a</sup>	.345	.338	7.63090	.345	49.612	.000
age/sex/disturbance	.625 <sup>b</sup>	.391	.364	7.48034	.046	2.274	.085
respite group	.755 <sup>c</sup>	.569	.545	6.32525	.178	37.271	.000

The second question to be answered in relation to this model was whether respite group predicted social activity at time 2. Figure 9.18 shows the active path tested in this step.

**Figure 9.18: Effect of respite on social activity**



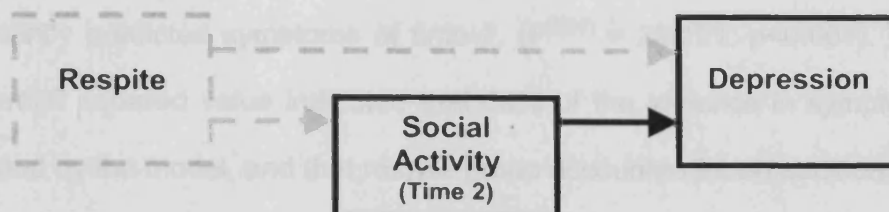
In this analysis, the total adjusted *R* squared value indicated that 36% of the variance in social activity was explained by the model ( $F^{(5,95)} = 11.75, p < 0.001$ ). However, respite group did not account for a significant amount of variance in social activity once the other factors had been controlled (see table 9.19).

**Table 9.19: Model Summary: Effect of Respite on Social Activity**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline activity	.570 <sup>a</sup>	.325	.318	6.20530	.325	45.814	.000
age/sex/disturbance	.625 <sup>b</sup>	.390	.364	5.99392	.065	3.273	.025
respite group	.626 <sup>c</sup>	.392	.359	6.01739	.002	.284	.596

To complete the analysis of the paths in the model, the extent to which social activity predicted depression at time 2 was examined (see figure 9.20).

Figure 9.20: Effect of Social Activity on Depression



The results of the analysis revealed that the variables significantly predicted depression at time 2, ( $F^{(5,95)} = 9.99$ ,  $p < 0.001$ ), explaining 36% of the variance in depression. However, unlike in the case of respite group, social activity did not add significantly to the model, accounting for only 1% of the additional variance in depression (see table 9.21).

Table 9.21: Model Summary: Effect of Social Activity on Depression

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline depression/activity	.592 <sup>a</sup>	.350	.336	7.67551	.350	24.785	.000
age/sex/disturbance	.627 <sup>b</sup>	.393	.359	7.54055	.043	2.108	.105
time 2 social activity	.637 <sup>c</sup>	.405	.365	7.50712	.012	1.794	.184

The suggestion from these analyses is that that while, respite group was strongly associated with depression (accounting for 18% of the variance in depression outcome after other factors were controlled), its effects were not mediated by changes in social activity from baseline to time 2.

## 4.2 Physical Symptoms

As with depression, the first question to be answered in relation to physical symptoms was whether respite group predicted symptoms at time 2. The results of the multiple regression analysis revealed that, taken together, the variables significantly predicted symptoms at time 2, ( $F^{(5,95)} = 29.151$ ,  $p < 0.001$ ). The total adjusted  $R$  squared value indicated that 59% of the variance in symptoms was explained by the model, and that respite group accounted for an additional 10% of the variance after the other variables had been controlled (change in  $R^2 = 0.10$ ,  $p < 0.001$ ) (see table 9.22 for summary of the model). The beta coefficient indicated a lower level of symptoms in the respite group ( $\beta = -0.33$ ,  $p < 0.001$ ).

**Table 9.22: Model Summary: The effect of respite on symptoms**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline symptoms	.708 <sup>a</sup>	.502	.496	2.97735	.502	97.584	.000
age/sex/disturbance	.718 <sup>b</sup>	.515	.494	2.98320	.014	.873	.458
respite group	.781 <sup>c</sup>	.610	.590	2.68787	.095	22.791	.000

As the previous results concerning depression had already indicated that respite group did not predict variance in social activity, the analysis then went on to examine whether social activity predicted symptoms at time 2.

The results of the analysis revealed that the variables significantly predicted symptoms at time 2, ( $F^{(5,95)} = 29.151$ ,  $p < 0.001$ ), with 59% of the variance in symptoms explained. However, unlike in the case of respite group, social activity did not add significantly to the model, accounting for only 1% of the additional variance in symptoms.

### 4.3 Objective Carer Burden

Using objective burden as the outcome, multiple regression analysis revealed that the variables significantly predicted burden at time 2, ( $F^{(5,95)} = 43.42$ ,  $p < 0.001$ ). The total adjusted  $R$  squared value indicated that 70% of the variance in burden was explained by the model. In contrast to the tests on depression and symptoms, in this case respite group accounted for the vast majority of the variance in outcome and explained 60% of the variance after other variables had been controlled (change in  $R^2 = 0.60$ ,  $p < 0.001$ ) (see table 9.23). The beta coefficient indicated a lower level of burden in the respite group ( $\beta = -0.87$ ,  $p < 0.001$ ).

**Table 9.23: Model Summary: The effect of respite on objective burden**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline obj. burden	.059 <sup>a</sup>	.004	-.007	5.38607	.004	.322	.572
age/sex/disturbance	.345 <sup>b</sup>	.119	.079	5.14998	.115	3.845	.012
respite group	.845 <sup>c</sup>	.714	.697	2.95157	.595	180.910	.000

Consistent with the previous results concerning depression and symptoms, regression analyses revealed that objective burden was not predicted by social activity, which accounted for only 1% of the variance in outcome.

### 4.4 Subjective Carer Stress

When subjective stress was examined as the outcome, multiple regression analysis again revealed that the variables entered into the equation significantly

predicted stress at time 2, ( $F^{(5,95)} = 19.00$ ,  $p < 0.001$ ). The total adjusted  $R$  squared value indicated that 50% of the variance in stress was explained by the model.

As in the case of objective burden, and in contrast to the tests on depression and symptoms, respite group accounted for the majority of the variance in outcome and explained 36% of the variance after other variables had been controlled (change in  $R^2 = 0.36$ ,  $p < 0.001$ ) (see table 9.24). The beta coefficient indicated a lower level of stress in the respite group ( $\beta = -0.66$ ,  $p < 0.001$ ).

**Table 9.24: Model Summary: The effect of respite on subjective stress**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline subj. stress	.175 <sup>a</sup>	.030	.020	3.76868	.030	2.862	.094
age/sex/disturbance	.408 <sup>b</sup>	.166	.128	3.55403	.136	4.775	.004
respite group	.722 <sup>c</sup>	.522	.495	2.70642	.356	64.752	.000

Once again, regression analyses revealed that subjective stress was not predicted by social activity, which accounted for only 1% of the variance in subjective burden responses at time 2 after other variables had been controlled.

#### 4.5 Subjective Demand

Concerning the final self-report outcome, subjective demand, multiple regression analysis again revealed that, in total, the variables entered into the equation significantly predicted burden at time 2, ( $F^{(5,95)} = 8.51$ ,  $p < 0.001$ ).

The total adjusted  $R$  squared value indicated that 29% of the variance in stress was explained by the model. Respite group alone accounted for nearly 20% of

the variance in outcome (change in  $R^2 = 0.19$ ,  $p < 0.001$ ) (see table 9.25). The beta coefficient indicated a lower level of demand in the respite group ( $\beta = -0.49$ ,  $p < 0.001$ ).

**Table 9.25: Model Summary: The effect of respite on subjective demand**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline subj. demand	.042 <sup>a</sup>	.002	-.009	2.57134	.002	.160	.690
age/sex/disturbance	.362 <sup>b</sup>	.131	.092	2.43959	.129	4.365	.006
respite group	.573 <sup>c</sup>	.328	.290	2.15703	.197	25.565	.000

As in previous analyses, using social activity as an independent variable, subjective demand was not predicted by social activity, which accounted for only 1% of the variance in subjective burden responses at time 2 after other variables had been controlled.

#### 4.6 Cortisol

The regression analyses conducted for the self-report outcomes were repeated to examine the extent to which cortisol outcomes were predicted by study group and by changes in social activity. In contrast to the results of the self-report outcome analyses, study group did not account for the variance in time 2 cortisol for any of the sampling times (10am, 2pm, 6pm and 10pm) (once baseline cortisol, age, sex and dependency were controlled. Changes in adjusted  $R^2$  on entering respite group into the equation ranged from 0.003 to 0.014 and were not significant. Regression analyses also revealed that social activity also did predict variance in cortisol at time 2 when sampled at 2pm, 6pm and 10pm. Changes in adjusted

$R^2$  on entering social activity into the equation ranged from 0.001 to 0.008 and were not significant.

In contrast to these findings however, and in contrast to the results for self-report outcomes, social activity was found to predict 10 am cortisol levels at time after baseline levels (and the other relevant factors) had been controlled. Overall, the factors explained 15% of the variance in 10am cortisol levels ( $F^{(5,95)} = 3.22$ ,  $p < 0.001$ ), with social activity alone accounting for 6% of the variance (change in adj  $R^2 = (0.06$ ,  $p < 0.05)$ ) (see table 9.26). Notably, increased levels of social activity were associated with higher levels of cortisol at time 2 ( $\beta = 0.32$ ,  $p < 0.05$ ).

**Table 9.26: Model Summary: The effect of social activity on cortisol**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline social activity and 10 am cortisol	.325 <sup>a</sup>	.106	.081	5.68698	.106	4.315	.017
age/sex/disturbance	.404 <sup>b</sup>	.164	.104	5.61645	.058	1.615	.194
time 2 soc.activity	.468 <sup>c</sup>	.219	.151	5.46769	.055	4.861	.031

## 5. Summary

The main aim of the analysis at time 2 was to examine the effect of respite care on outcome, as well as to examine whether changes in social activity from baseline to time 2 moderated and/or mediated this effect. Two groups were created to represent a) those carers reporting an increase in positive social activity from before to during respite, and b) those reporting no change or a decrease in social activity. A greater proportion of women reported an increase in social activity than men.



After controlling for baseline, carers in the respite group exhibited lower levels of all self-report outcomes at time 2 in comparison to controls. This effect of respite care intervention was independent of carers' age, sex and the initial level of dependency. In contrast to the findings for the self-report variables, however, no effect of respite group or social activity was observed on cortisol outcomes.

Except in the case of subjective carer demand, the effect of respite on outcome differed according to whether or not social activity had increased from baseline. Specifically, the effect of respite was greater among those reporting an increase in social activity than those reporting no change or a decrease in activity.

Mediation analyses revealed that respite group accounted for a significant amount of variance in all of the self-report outcomes. However, the analyses also revealed that respite group did not predict changes in social activity. This indicated that, although the effect of respite may be moderated by changes in social activity, its effects were not mediated by this factor.

Consistent with this conclusion, social activity did not predict outcome in terms of any of the self-report variables. In contrast, however, study group did predict 10 am cortisol levels. Notably, and also in contrast to the effect on self-reported outcomes, the results indicated that increased levels of social activity were associated with higher levels of 10 am cortisol at time 2.

## **Chapter 10: Time 3 Results**

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## **1. Introduction**

The purpose of the time 3 analyses was to examine the effect of study group (respite versus no respite) on outcomes one week after respite had ended (or the equivalent time point for controls). In addition, the aim was to examine the conditions under which this effect is either moderated and/or mediated by changes in social activity from baseline to time 2, and additionally, by changes in care recipient disturbance (or 'dependency') from baseline to time 3.

As at the time 2 stage, analyses began with an examination of the role of the third variables in moderating the effects of respite (using a 2x2 design), and then went on to investigate whether these variables exerted mediating effects.

## **2. Increased versus Unchanged or Decreased Dependency**

Changes in dependency from baseline to time 2 were normally distributed around a mean decrease of - 0.19 (median = 0) (95% CI = -5.00 to +6.80). The correlation between dependency at times 1 and 3 was 0.84 ( $p < 0.001$ ) demonstrating an acceptable level of test-retest reliability. Analyses of covariance were performed to examine whether respite provision and/or dementia diagnosis had an effect on dependency at time 3 (with baseline levels of dependency controlled). The analysis revealed no main effects of either factor or any interactive effect on changes in dependency.

As was the case for social activity, two groups were created to represent a) carers reporting an increase in dependency from before to after respite, and b) those reporting no change or a decrease in dependency (see the Methods chapter for a justification of this approach). The difference between the two

groups on the continuous measure of change in dependency was significant ( $F=156.10$ ,  $df=1,97$ ,  $p<0.001$ ).

**Table 10.1: Changes in dependency from before to 1 week after respite**

	N	Mean	Std. Deviation	95% Confidence Interval	
				Lower Bound	Upper Bound
not increased	60	-2.0167	1.73197	-2.4641	-1.5693
increased	41	2.4932	1.85200	1.9086	3.0777

The 'increased' and 'not increased' groups did not differ in relation to age, sex, diagnosis of care recipient or respite group allocation. Analysis of variance did reveal, however, that the groups differed in relation to the baseline level of dependency, with those reporting an increase in dependency rating baseline levels as significantly lower ( $F=14.13$ ,  $df=100$ ,  $p<0.001$ ). Adding the study group (respite vs control) as a factor into this analysis showed that the difference between the dependency-increased and not increased groups on baseline levels dependency did not differ according to whether or not they received respite. Rather, low levels of baseline dependency were associated with subsequent increases in dependency in both study groups.

### **3. Tests of Direct and Moderating Effects**

In addition to the overall effect of group on outcome, the interactions between group and change in social activity (baseline to time 2), and between group and change in dependency (baseline to time 3), were entered into the time 3 analysis. Of interest was whether the effect of group varied at different levels of the third variables.

Two-way (2x2) Analyses of Covariance were performed for each of the outcome measures. In each analysis, the dependant variable was the outcome at time 3,

with outcome measures at baseline controlled for as covariates. Age, sex and baseline level of care recipient dependency were also entered into the analyses as covariates to control for their effects.

### 3.1 Depression

Table 10.2 compares depression levels at time 3 (baseline adjusted) between the two study groups by change in social activity, while table 10.3 illustrates the outcome for study group by change in dependency.

**Table 10.2: Depression at time 3 (baseline adjusted) by study group and change in social activity**

group	change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	17.377 <sup>a</sup>	1.287	14.815	19.939
	increased	15.880 <sup>a</sup>	1.377	13.140	18.621
respite	not increased	11.252 <sup>a</sup>	1.554	8.158	14.346
	increased	11.553 <sup>a</sup>	1.571	8.426	14.679

**Table 10.3: Depression at time 3 (baseline adjusted) by study group and change in dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	13.296 <sup>a</sup>	1.228	10.858	15.735
	increased	19.586 <sup>a</sup>	1.409	16.787	22.386
respite	not increased	10.396 <sup>a</sup>	1.254	7.905	12.887
	increased	11.390 <sup>a</sup>	1.588	8.235	14.545

Analyses of covariance revealed a significant main effect of respite group ( $F=12.14$ ,  $df=1,98$ ,  $p<0.01$ ), with those receiving respite exhibiting lower levels of depression at time 3 in comparison to controls (see figure 10.4). This effect of group did not differ by change in social activity or by change in dependency. However, the results did indicate a main effect of dependency change on

depression ( $F=7.35$ ,  $df=1,98$ ,  $p<0.01$ ) (see figure 10.5). With those reporting an increase in dependency also reporting higher levels of depression at follow up.

Figure 10.4: Effects of respite on depression

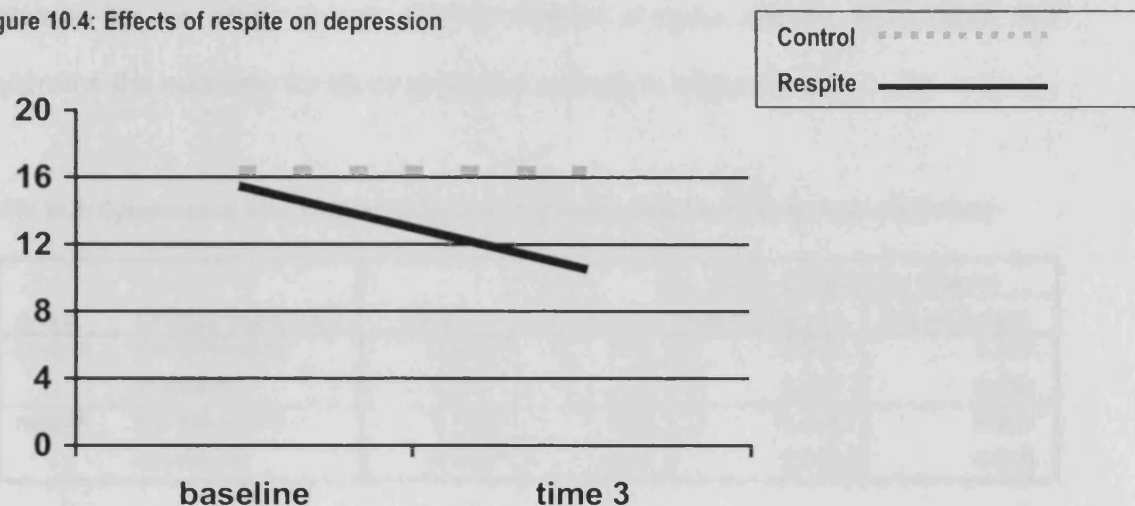
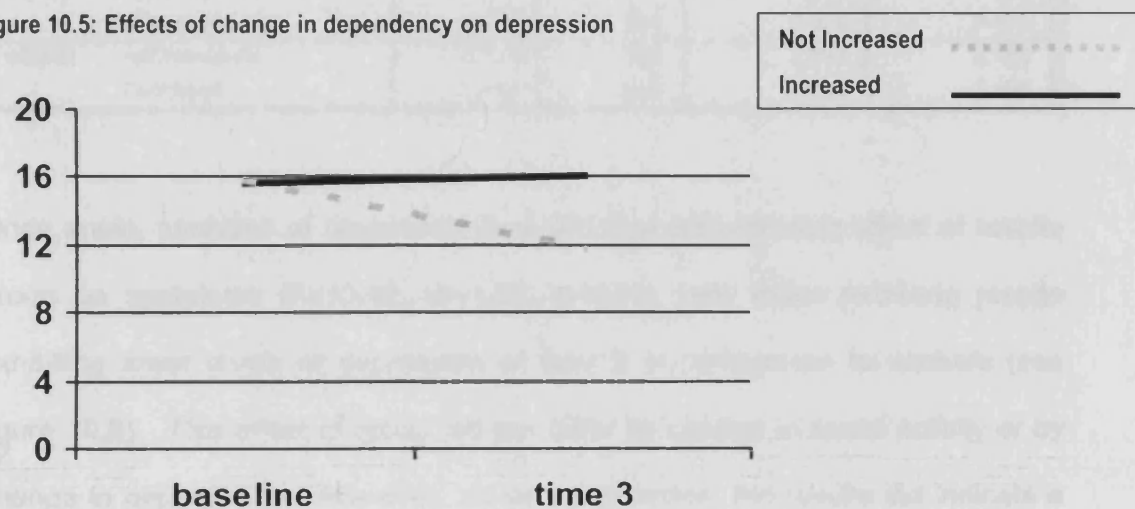


Figure 10.5: Effects of change in dependency on depression



### 3.2 Physical Symptoms

Table 10.6 compares physical symptom levels at time 3 (baseline adjusted) between the two study groups and by change in social activity, while table 10.7 illustrates the outcome for study group by change in dependency.

**Table 10.6: Symptoms at time 3 (baseline adjusted) by study group and change in social activity**

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	6.914 <sup>a</sup>	.473	5.973	7.855
	increased	7.277 <sup>a</sup>	.513	6.257	8.298
respite	not increased	5.790 <sup>a</sup>	.575	4.646	6.933
	increased	4.896 <sup>a</sup>	.549	3.803	5.989

**Table 10.7: Symptoms at time 3 (baseline adjusted) by study group and change in dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	5.772 <sup>a</sup>	.457	4.862	6.681
	increased	8.420 <sup>a</sup>	.528	7.369	9.471
respite	not increased	4.703 <sup>a</sup>	.534	3.641	5.766
	increased	5.983 <sup>a</sup>	.604	4.780	7.185

Once again, analyses of covariance revealed a significant main effect of respite group on symptoms ( $F=10.42$ ,  $df=1,98$ ,  $p<0.01$ ), with those receiving respite exhibiting lower levels of depression at time 3 in comparison to controls (see figure 10.8). This effect of group did not differ by change in social activity or by change in dependency. However, as with depression, the results did indicate a main effect of dependency change on symptoms ( $F=12.00$ ,  $df=1,98$ ,  $p<0.01$ ) (see figure 10.9).

Figure 10.8: Effects of respite on symptoms

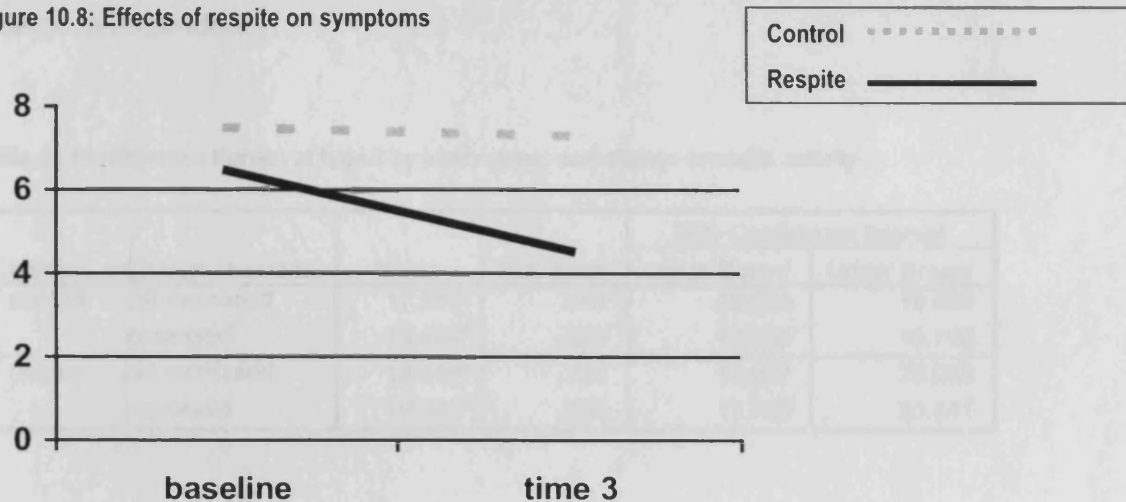
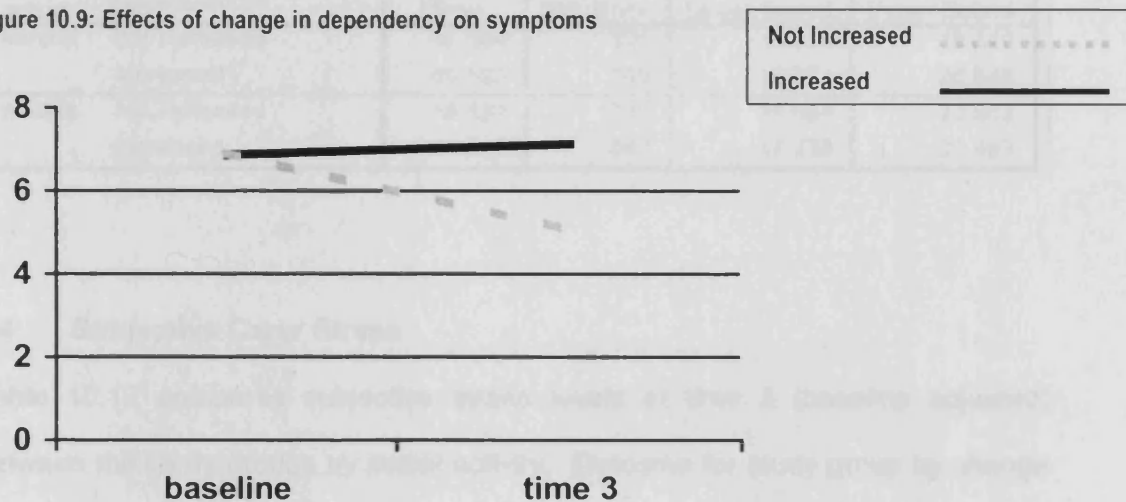


Figure 10.9: Effects of change in dependency on symptoms



### 3.3 Objective Carer Burden

Table 10.10 compares burden levels at time 3 (baseline adjusted) between the two study groups by change in social activity, while table 10.11 illustrates the outcome for study group by change in dependency. In contrast to the results for



depression and physical symptoms, analyses of covariance did not reveal an effect of respite group or any of the third variables on objective carer burden at time 3. Neither were there any effects of group by change in social activity or by change in dependency.

**Table 10.10: Objective Burden at time 3 by study group and change in social activity**

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	17.813 <sup>a</sup>	.641	16.536	19.090
	increased	18.464 <sup>a</sup>	.670	17.130	19.798
respite	not increased	18.498 <sup>a</sup>	.789	16.927	20.069
	increased	19.342 <sup>a</sup>	.753	17.843	20.841

**Table 10.10: Objective Burden at time 3 by study group and change in dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	17.144 <sup>a</sup>	.605	15.939	18.349
	increased	19.133 <sup>a</sup>	.709	17.721	20.546
respite	not increased	19.124 <sup>a</sup>	.733	17.664	20.583
	increased	18.716 <sup>a</sup>	.847	17.030	20.403

### 3.4 Subjective Carer Stress

Table 10.12 compares subjective stress levels at time 3 (baseline adjusted) between the study groups by social activity. Outcome for study group by change in dependency are presented in table 10.13.

As with the analysis on objective burden, analyses of covariance did not reveal an effect of respite group or any of the third variables on subjective stress at time 3. Once again, neither were there any effects of group by change in social activity or by change in dependency.

**Table 10.12: Subjective Stress at time 3 by study group and change in social activity**

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	13.381 <sup>a</sup>	.483	12.419	14.342
	increased	13.632 <sup>a</sup>	.524	12.588	14.675
respite	not increased	12.892 <sup>a</sup>	.600	11.696	14.088
	increased	13.158 <sup>a</sup>	.589	11.985	14.330

**Table 10.13: Subjective Stress at time 3 by study group and change in dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	12.702 <sup>a</sup>	.470	11.766	13.639
	increased	14.310 <sup>a</sup>	.551	13.213	15.407
respite	not increased	12.827 <sup>a</sup>	.545	11.742	13.913
	increased	13.222 <sup>a</sup>	.663	11.903	14.542

### 3.5 Subjective Demand

Table 10.14 compares subjective demand levels at time 3 (baseline adjusted) between the study groups by social activity.

**Table 10.14: Subjective Demand at time 3 by study group and change in social activity**

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	12.284 <sup>a</sup>	.307	11.672	12.896
	increased	12.267 <sup>a</sup>	.335	11.599	12.935
respite	not increased	12.948 <sup>a</sup>	.383	12.185	13.711
	increased	12.571 <sup>a</sup>	.377	11.820	13.322

Once again, analyses of covariance did not reveal an effect of respite group or any of the third variables on subjective demand at time 3. Neither were there any effects of group by change in social activity or by change in dependency.

### 3.6 Cortisol

As in the analysis of time 2 data, cortisol was examined by time of day point so as to allow the identification of any different effects at each sampling point. Table 10.15 presents the change from baseline to time 3 in cortisol levels by group for 10 am, 2pm, 6pm and 10pm samples.

**Table 10.15: Cortisol at baseline and time 3 by group (split by sampling time)**

10 am					2pm				
	control		respite			control		respite	
	Mean	Std	Mean	Std		Mean	Std	Mean	Std
baseline	9.74	6.30	8.92	6.00	baseline	6.55	4.71	8.11	4.89
time 3	7.00	5.01	9.62	6.40	time 3	5.21	4.30	6.62	4.12

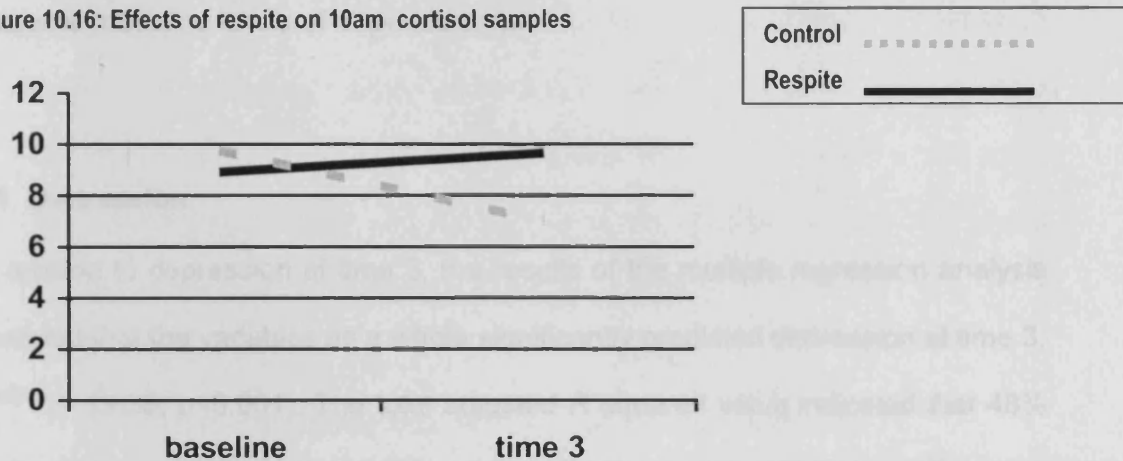
  

6 pm					10 pm				
	control		respite			control		respite	
	Mean	Std	Mean	Std		Mean	Std	Mean	Std
baseline	3.81	2.60	4.97	3.21	baseline	2.67	1.49	2.62	1.48
time 3	4.27	3.44	6.00	3.69	time 3	2.25	1.12	2.47	1.38

Analyses of covariance revealed a significant main effect of respite group on 10 am cortisol levels ( $F=6.20$ ,  $df=1,98$ ,  $p<0.05$ ). In contrast to the effect of group on depression and physical symptom levels, the respite group actually exhibited higher 10 am cortisol levels at time than the control group. Figure 10.16 shows that this effect was a product of both a rise in respite group cortisol levels from baseline to follow up, along with an accompanying drop in cortisol levels among the control group. No other significant effects were revealed in the analysis of 10 am cortisol. Additionally, no significant main effects, or group by third variable

effects were observed on any of the other cortisol samples (ie – 2pm, 6pm and 10pm).

Figure 10.16: Effects of respite on 10am cortisol samples



#### 4. Tests of Mediating Effects

The previous analyses of variance established that there was an effect of respite upon depression and physical symptoms, with the respite group reporting lower levels on both outcomes at time 3 in comparison to controls (after adjusting for baseline). In addition, respite group also had an effect upon 10 am cortisol levels at time 3, only this time the effect was to increase cortisol in comparison to controls.

Although there were no moderating effects revealed for either social activity or dependency, tests for mediating effects were still carried out. This is because, as mentioned in the methods chapter, it is possible that a mediation effect may exist even where a moderation effect does not. As in the time 2 data analyses, mediating effects were tested using multiple linear regression.

Once again, variables were selected for entry into the regression analyses if they functioned as baseline variables, demographics, independent (predictor) variables or differed significantly between the study groups while also being related to outcome (baseline levels of dependency).

#### 4.1. Depression

In relation to depression at time 3, the results of the multiple regression analysis revealed that the variables as a whole significantly predicted depression at time 3, ( $F^{(5,98)} = 19.38, p < 0.001$ ). The total adjusted *R* squared value indicated that 48% of the variance in depression was explained by the model, and that respite group accounted for 6% of the variance after the other variables had been controlled (see table 10.17 for summary of the model). The beta coefficient indicated a lower depression level in the respite group ( $\beta = -0.28, p < 0.001$ ).

**Table 10.17: Model Summary: Effect of respite on depression**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline depression	.634 <sup>a</sup>	.402	.396	7.22400	.402	65.192	.000
age/sex/disturbance	.670 <sup>b</sup>	.449	.426	7.04219	.047	2.691	.051
respite group	.714 <sup>c</sup>	.510	.484	6.67599	.061	11.595	.001

From previous analyses of the time 2 data, it had already been established that respite group did not have an effect on changes in social activity from baseline to time 2. Regression analyses of time 3 data also indicated that respite group did not predict change in dependency.

To complete the analysis of the paths in the model, the extent to which changes in social activity and dependency predicted depression at time 3 was examined.

Regression analyses, with time 3 outcome as the dependant variable, were used to examine the amount of variance explained by both social activity and dependency (after controlling for baseline levels of these variables along with age and sex). The results indicated that while social activity was unrelated to depression at time 3, dependency explained 6% of the variance in outcome after all other variables had been controlled (adjusted  $R^2 = 0.06$ ,  $p < 0.01$ ) (see table 10.18). The beta coefficient showed that rises in dependency were associated with increased levels of depression (beta= 0.43,  $p < 0.01$ ).

**Table 10.18: Model Summary: Effect of social activity and dependency on depression**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline depression & activity	.649 <sup>a</sup>	.421	.409	7.17748	.421	34.585	.000
age/sex/disturbance	.681 <sup>b</sup>	.464	.435	7.01751	.043	2.460	.068
time 3 activity	.705 <sup>c</sup>	.497	.464	6.83803	.033	5.893	.017
time 3 disturbance	.745 <sup>d</sup>	.555	.520	6.47020	.058	11.641	.001

## 4.2 Physical Symptoms

Concerning physical symptoms at time 3, the results of the multiple regression analysis revealed that, taken together, the variables as a whole significantly predicted symptoms at time 3, ( $F^{(5,98)} = 41.77$ ,  $p < 0.001$ ). The total adjusted  $R$  squared value indicated that 67% of the variance in symptoms was explained by the model, and that respite group accounted for 4% of the variance after the other variables had been controlled (see table 10.19 for summary of the model). The beta coefficient, as in the case of depression, indicated a lower physical symptom level in the respite group (beta = - 0.21,  $p < 0.01$ ).

**Table 10.19: Model Summary: Effect of respite on symptoms**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline symptoms	.790 <sup>a</sup>	.624	.620	2.66270	.624	164.442	.000
age/sex/disturbance	.808 <sup>b</sup>	.653	.638	2.60015	.028	2.607	.056
respite group	.829 <sup>c</sup>	.687	.671	2.47929	.035	10.587	.002

To complete the analysis of physical symptoms at time 3, the extent to which changes in social activity and dependency predicted this outcome was examined. Regression analyses, with time 3 symptoms as the dependant variable, were used to examine the amount of variance explained by both social activity and dependency (after controlling for baseline levels of these variables along with age and sex). The results again indicated that while social activity was unrelated to symptoms at time 3, dependency explained 3% of the variance in outcome after all other variables had been controlled (adjusted  $R^2 = 0.03$ ,  $p < 0.01$ ) (see table 10.20). The beta coefficient showed that rises in dependency were associated with increased levels of depression (beta= 0.28,  $p < 0.01$ ).

**Table 10.20: Model Summary: Effect of social activity and dependency on symptoms**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline symptoms & activity	.798 <sup>a</sup>	.636	.628	2.65799	.636	83.874	.000
age/sex/disturbance	.816 <sup>b</sup>	.666	.648	2.58739	.030	2.770	.046
time 3 activity	.820 <sup>c</sup>	.673	.651	2.57431	.007	1.948	.166
time 3 disturbance	.835 <sup>d</sup>	.698	.674	2.48866	.025	7.441	.008

### 4.3 Objective Carer Burden

Concerning objective burden at time 3, the results of the multiple regression analysis revealed that, taken together, the variables as a whole did not significantly predict outcome, with the total adjusted  $R$  squared value indicated that less than 5% of the variance in burden was explained by the model (and that

respite group accounted for less than 1% of the variance after the other variables had been controlled).

The extent to which changes in social activity and dependency predicted objective burden at time 3 was also examined. The results indicated that neither of these variables accounted for a significant amount of variance in objective burden, with all the variables together explaining less than 1% of the variance in outcome.

#### **4.4 Subjective Carer Stress**

Concerning subjective stress, once again the results of the multiple regression analysis revealed that, taken together, the variables as a whole did not significantly predict outcome, with the total adjusted *R* squared value indicated that just over 1% of the variance in burden was explained by the model (and that respite group accounted for less than 0.5% of the variance after the other variables had been controlled). The results also indicated that neither social activity nor dependency accounted for a significant amount of variance in subjective stress outcomes at time 3.

#### **4.5 Subjective Carer Demand**

In relation to subjective demand, the pattern of results found for objective burden and subjective stress continued. Multiple regression analysis revealed that, taken together, the variables as a whole did not significantly predict outcome, with the total adjusted *R* squared value indicating that less than 1% of the variance in subjective demand was explained by the model. The results also indicated that



neither social activity nor dependency accounted for a significant amount of variance in subjective demand.

#### 4.6 Cortisol

In the previous moderating analyses, respite was only found to have an effect on the 10 am sample outcome. In relation to 10 am cortisol outcomes, regression analyses revealed that the variables entered into the regression equation significantly predicted outcome at time 3, ( $F^{(5,91)} = 2.84$ ,  $p < 0.05$ ). The total adjusted *R* squared value indicated that the model explained 12% of the variance in 10 am cortisol, and that virtually all of this variance was explained by respite (see table 10.21 for summary of the model).

**Table 10.21: Model Summary: Effect of respite on 10 am cortisol**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline 10 am cortisol	.225 <sup>a</sup>	.050	.036	5.50292	.050	3.609	.062
age/sex/distribution	.254 <sup>b</sup>	.064	.007	5.58705	.014	.323	.809
respite group	.426 <sup>c</sup>	.182	.118	5.26611	.117	9.164	.004

The beta coefficient, in contrast to the analysis on depression and physical symptom outcomes, indicated a higher 10am cortisol level in the respite group ( $\beta = 0.38$ ,  $p < 0.01$ ). In contrast to the 10 am outcome, however, study group predicted no other cortisol sample levels at time 3.

The extent to which changes in social activity and dependency predicted 10 am cortisol was also examined. Regression analyses, with time 3 outcome as the dependant variable, were used to examine the amount of variance explained by both social activity and dependency (after controlling for baseline levels of these variables along with age and sex). The results indicated that only 4% of the

variance in 10am cortisol was explained by all the variables entered, which was not significant. Similarly, neither social activity nor dependency were useful in predicting 2pm, 6pm or 10pm cortisol levels.

## **5. Carers' Evaluation of Respite**

In addition to the data on self reported well-being and cortisol, the data on carers' own evaluations of the respite care intervention were analysed. Negative items (eg – item 6: "I feel slightly worse after this respite period than before it") were reversed scored so that a higher score indicated a more positive rating. The findings (obtained just from the respite group) indicated that scores on the questionnaire were normally distributed and that the scale had excellent internal reliability ( $\alpha = 0.92$ ).

The factor structure of the scale was examined using principle component analysis. This technique converts a large number of related variables into a smaller set of 'factors'. Each factor is composed of a weighted set of the original variables. The weights (factor loadings) or coefficients are selected to render each factor independent of the others and to sequentially explain the largest amount of the total variance possible. A subsequent Varimax rotation was used that minimises the number of variables that have high loadings on each factor and simplifies the interpretation of the factors.

The analysis revealed three factors that, between them explained 76% of the total variance in all the items. The factors and the items that loaded on to them are presented in table 10.22. A loading of over 0.60 was used as the criteria for attributing items to factors.

**Table 10.22: Component matrix for the items on the Respite Evaluation Scale (n=51)**

	Component		
	1	2	3
This latest respite period enabled me to really relax and enjoy life	.423	.054	.798
This latest respite period left me feeling fed up	.801	.093	.310
This latest respite period helped me to 'recharge my batteries'	.584	.161	.637
This latest respite period had a bad as well as good effect on me	.731	.329	.181
I feel much better after this respite period	.823	.220	.360
I feel slightly worse after this respite period than before it	.890	.092	.202
The respite enabled me to make contact with and enjoy the company of others	.090	-.016	.914
I feel I had the 'skills' to benefit fully from this latest respite period	.251	.100	.647
My spouse did not like this latest respite period	.114	.837	.224
The effect of this latest respite period on my spouse caused me concern	.625	.531	.299
I think my spouse enjoyed this latest respite period	.048	.880	.107
This latest respite period did my spouse a lot of good	.211	.863	.142
My spouse returned home worse after this latest respite period	.557	.668	-.097
My spouse seems happier after this latest respite period	.196	.792	-.195

The first factor and was made up of 5 items ( $\alpha=0.91$ ) and tapped into the *carer effects* of respite, including feelings of being 'fed up' and feeling 'better'. The second factor was made up five items ( $\alpha = 0.89$ ) and tapped into the *care-recipient effects* of respite. Finally, the third factor was made up of four items ( $\alpha =0.85$ ) and addressed the *functions of respite*, and the extent to which carers 'made use' of respite such as to relax, 'recharge batteries' or engage in social activity. This factor was also informed by whether carers felt they had the 'skills' to make use of respite.

It was notable that the item pertaining to whether the effect of respite on the care recipient caused the carer concern loaded slightly higher on the '*carer effects*' factor than on the '*care recipient effects*' factor. This may be because it directly asked about the carers' their own feelings of concern and hence tapped into their own affective responses.

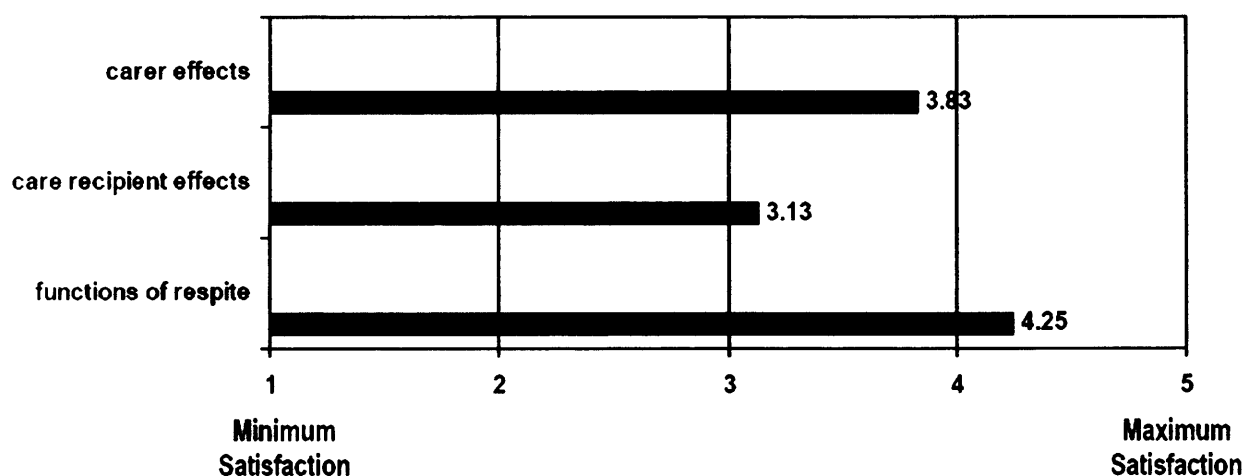
In relation to the intercorrelations between the three sub-scales, the carer effects and care recipient effects factors were positively associated ( $r=0.56$ ,  $p<0.001$ ), as

were the carer effects and functions of respite factors ( $r=0.67$ ,  $p<0.001$ ). However, there was no significant association between the care recipient effects and functions of respite factors.

Figure 10.23 compares participants' mean scores on the three respite evaluation subscales. As the three subscales were made up of different numbers of items the mean scores were divided by the number of items summed so as to make the subscales comparable (ie – with a minimum score of 1 and a maximum score of 5).

As is evident from figure 10.23, carers gave evaluation ratings on all three subscales that were over the half-way point. The highest evaluation ratings were given in relation to the functions of respite subscale while carers expressed the lowest scores on the care recipient effects subscale. Paired t-tests revealed that the differences between scores on all three factors were significant ( $t=3.90$  to  $7.34$ ,  $df=50$ ,  $p<0.001$ ).

**Figure 10.23: Carers' ratings on the three respite evaluation subscales**



Regression analyses were performed in order to investigate whether carers evaluations of respite were predicted by any carer or care recipient characteristics (as assessed before respite at baseline).

In relation to evaluations on the carer effects subscale, the analysis revealed that, although neither age, sex or dependency were associated with outcome, diagnosis did predict outcome, with higher ratings being made by carers of someone with dementia (beta = 0.48,  $p < 0.01$ ). Dementia diagnosis accounted for 17% of the variance in ratings on the carer effects subscale even after the demographic and dependency variables had been controlled (see figure 10.24).

Figure 10.24: Model Summary: Predictors of Respite Evaluations (Carer Effects Subscale)

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
age	.189	.036	-.015	4.77708	.036	.702	.502
sex	.298	.089	.015	4.70562	.053	2.163	.150
dependency	.407	.166	.073	4.56528	.077	3.310	.077
dementia diagnosis	.579	.335	.240	4.13438	.169	8.895	.005

Regression analyses revealed that none of the carer or care recipient variables were associated with evaluations on the care recipient effects subscale. However, in relation to the functions of respite subscale, the sex of the carer emerged as a significant predictor, accounting for 10% of the variance in carers ratings. Women rated their satisfaction on this subscale significantly higher than did men (beta = -0.34,  $p < 0.05$ ).

Regression analyses were also conducted to examine the extent to which evaluations of respite were associated with changes in outcome. Specifically of

interest was the extent to which the *carer effects* subscale predicted changes in depression, the extent to the *care recipient* effects subscale predicted changes in care recipient dependency, and the extent to which the *functions of respite* subscale predicted changes in social activity.

In relation to the first question, regression analyses with depression at time 3 as the criterion and the three respite evaluation subscales as the independent variables showed that the *carer effects* subscale did indeed significantly predict changes in depression. After controlling for baseline depression levels, evaluations of *carer effects* were positively associated with time 3 depression levels and accounted for 7% of the variance in outcome ( $\beta = -0.42$ ,  $p < 0.05$ ). Neither of the other two subscales were related to depression. In relation to the second and third questions, regression analyses revealed that none of the three respite evaluation subscales predicted dependency or social activity.

## 6. Summary

Like at time 2, the aim of the analysis at time 3 was to examine the effect of respite care on outcome, and again to look at whether changes in social activity from baseline to time 2 moderated and/or mediated this effect. In addition, time 3 analyses also examined the extent to which the effects of respite differed according to whether or not care recipient dependency increased from baseline to time 3. Preliminary analyses revealed that increases in dependency were not associated with respite care intervention or a dementia diagnosis.

Carers in the respite group exhibited lower levels of depression and physical symptoms at time 3 in comparison to controls. This effect was independent of carers' age, sex and the initial level of dependency. Unlike at time 2, however, there was no such effect of respite on any of the three carer burden outcomes. Also in contrast to the time 2 results, the effect of respite outcome was not moderated by changes in social activity or dependency.

The results did indicate, however, that changes in dependency had a direct effect on outcome. Specifically, those reporting an increase in dependency also reported higher levels of depression and physical symptoms at follow up (regardless of study group) after controlling for baseline levels.

In relation to cortisol, the results revealed a significant effect of respite on 10 am cortisol levels at time 3. As in the case of depression and physical symptoms, this effect was independent of carers' age, sex and the initial level of dependency. However, in contrast to the effect of respite on the self-report outcomes, 10 am cortisol was actually higher among the respite group than among controls. This was due to a rise in respite group cortisol levels from baseline to follow up, along with an accompanying drop in cortisol levels among the control group.

Mediation analyses indicated that respite group accounted for a significant amount of the variance in depression and symptoms at time 3 after all other variables had been controlled. In contrast, the results also indicated that membership of the respite group was associated with higher 10am cortisol levels. Respite group, however, did not predict any of the carer burden outcomes at this time point.

The results also revealed that, as in the case of social activity, study group did not predict changes in dependency from baseline to time 3, suggesting that respite care had no effect on this variable, and that its effects on outcome were not mediated by it.

While social activity was unrelated to outcome at time 3, the results indicated that rises in dependency were significantly associated with increased levels of both depression and symptoms. This was the case whether or not respite care had been provided.

Finally, an analysis of carers' own evaluation of the respite period suggested that this evaluation tapped into three factors. These were the *carer effects* of respite, the *care-recipient effects* of respite, and the *functions* of respite. There was no significant association between the care recipient effects and functions of respite factors. Carers' evaluations of the carer effects of respite were, however, a significant predictor of changes in depression levels between baseline and one week after respite. It was also notable that higher ratings were made on this subscale by carers of someone with dementia.



## **Chapter 11: Time 4 Results**

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### **2. Tests of Direct and Moderating Effects**

#### **2.1 Depression**

#### **2.2 Physical Symptoms**

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### **3. Tests of Mediating Effects**

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#### **3.3 Objective Carer Burden**

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#### **3.6 Cortisol**

### **4. Summary**

## **1 Introduction**

The purpose of the time 4 analyses was to examine the effect of study group (respite versus no respite) on outcomes at three weeks post respite intervention (or the equivalent time point for controls). As in the analyses of time 3 data, the aim was to examine the conditions under which this effect is either moderated and/or mediated by changes in social activity from baseline to time 2, and additionally, by changes in care recipient dependency from baseline to time 3. Analyses again began with an examination of the role of the third variables in moderating the effects of respite (using a 2x2 design), and then went on to investigate whether these variables exerted mediating effects.

## **2 Tests of Direct and Moderating Effects**

The overall effect of group on outcome, as well as how the effect of group varied at different levels of the third variables, was examined using two-way (2x2) analyses of covariance for each of the outcome measures. In each analysis, the dependant variable was outcome at time 4, with outcome measures at baseline controlled for as covariates. Age, sex and baseline level of care recipient dependency were also entered into the analyses as covariates to control for their effects.

As at time 3, the association of day care receipt with outcome variables was examined as this variable differed significantly between the two study groups at all time points. Independent t-tests were performed to compare the time 4 mean scores on outcomes of those carers reporting receipt of day care in the previous week and those not reporting any day care. As at time 3, no significant differences were found.

## 2.1 Depression

Table 11.1 compares depression levels at time 4 (baseline adjusted) between the two study groups by change in social activity, while table 11.2 illustrates the outcome for study group by change in dependency.

**Table 11.1: Depression at time 4 (baseline adjusted) by study group and change in social activity**

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	15.503 <sup>a</sup>	1.266	12.976	18.029
	increased	12.060 <sup>a</sup>	1.405	9.256	14.864
respite	not increased	13.498 <sup>a</sup>	1.570	10.365	16.631
	increased	11.867 <sup>a</sup>	1.479	8.915	14.820

**Table 11.2: Depression at time 4 (baseline adjusted) by study group and change in dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	13.702 <sup>a</sup>	1.205	11.296	16.107
	increased	13.861 <sup>a</sup>	1.509	10.848	16.873
respite	not increased	11.507 <sup>a</sup>	1.460	8.592	14.422
	increased	13.858 <sup>a</sup>	1.624	10.616	17.100

Analyses of covariance revealed no significant main effect of group, social activity or dependency on depression levels at time 4. In addition, the effect of group on depression did not significantly differ according to changes in social activity from baseline to time 2, or changes in dependency from baseline to time 3.

## 2.2 Physical Symptoms

Table 11.3 compares physical symptom levels at time 4 (baseline adjusted) between the two study groups by change in social activity, while table 11.4 illustrates the outcome for study group by change in dependency.

**Table 11.3: Symptoms at time 4 (baseline adjusted) by study group and change in social activity**

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	7.161 <sup>a</sup>	.577	6.011	8.312
	increased	7.339 <sup>a</sup>	.645	6.052	8.625
respite	not increased	6.072 <sup>a</sup>	.728	4.619	7.526
	increased	4.591 <sup>a</sup>	.643	3.307	5.874

**Table 11.4: Symptoms at time 4 (baseline adjusted) by study group and change in dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	6.241 <sup>a</sup>	.543	5.158	7.324
	increased	8.259 <sup>a</sup>	.681	6.901	9.617
respite	not increased	4.320 <sup>a</sup>	.659	3.005	5.635
	increased	6.343 <sup>a</sup>	.715	4.916	7.770

In contrast to the findings for depression outcome, analyses of covariance revealed a significant main effect of respite group on symptoms at time 4 ( $F=8.42$ ,  $df=1,88$ ,  $p<0.01$ ), with those receiving respite exhibiting lower levels of depression at time 4 in comparison to controls (see figure 11.5).

**Figure 11.5: Effects of respite on symptoms**

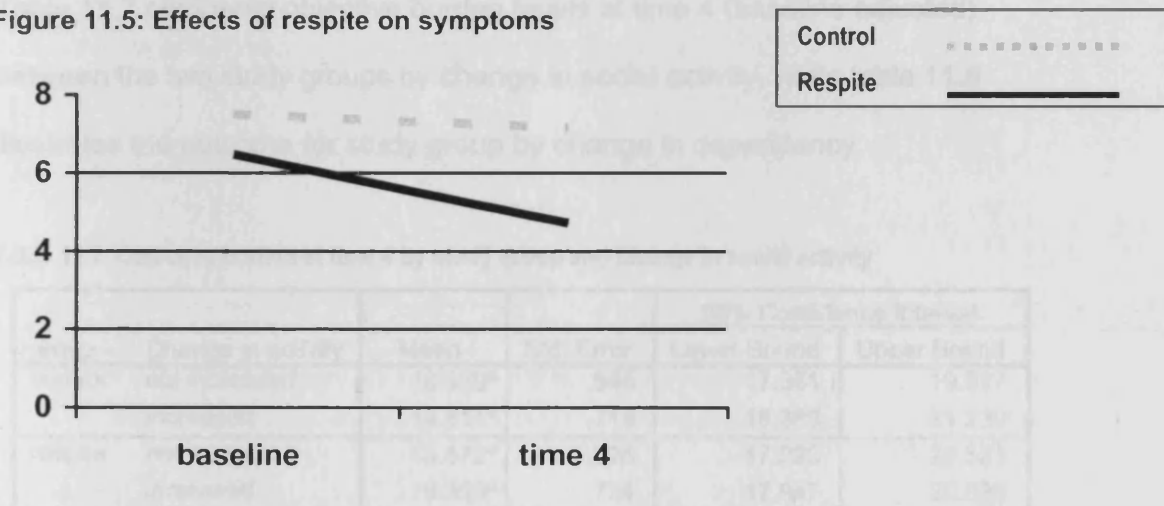
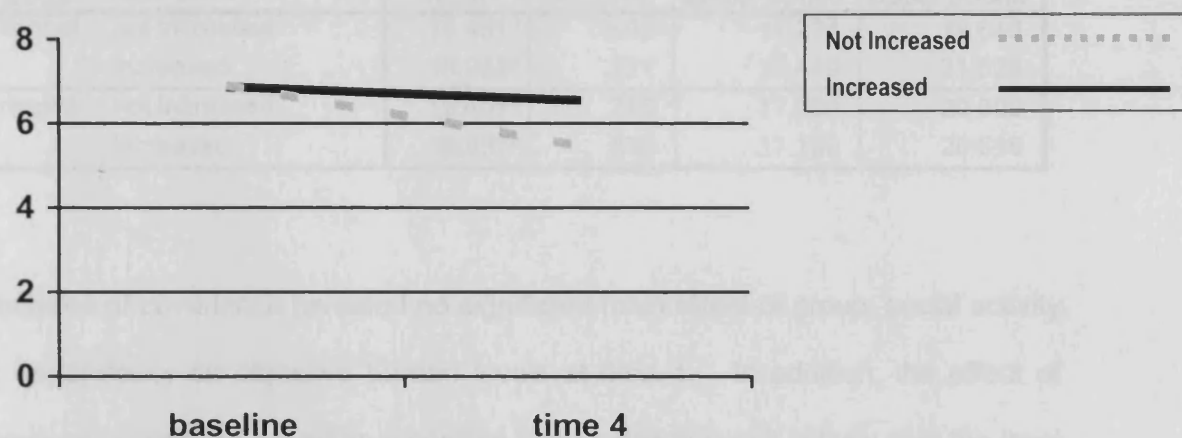


Figure 11.6: Effects of change in dependency on symptoms



This effect of group did not differ by change in social activity or by change in dependency. However, the results did indicate a main effect of dependency change on symptoms ( $F=8.43$ ,  $df=1,91$ ,  $p<0.01$ ) (see figure 11.6).

## 2.3 Objective Carer Burden

Table 11.7 compares objective burden levels at time 4 (baseline adjusted) between the two study groups by change in social activity, while table 11.8 illustrates the outcome for study group by change in dependency.

Table 11.7: Objective burden at time 4 by study group and change in social activity

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	18.639 <sup>a</sup>	.645	17.351	19.927
	increased	19.811 <sup>a</sup>	.715	18.383	21.239
respite	not increased	18.872 <sup>a</sup>	.826	17.223	20.521
	increased	19.393 <sup>a</sup>	.724	17.947	20.839

**Table 11.8: Objective Burden at time 4 by study group and dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	18.461 <sup>a</sup>	.595	17.274	19.649
	increased	19.988 <sup>a</sup>	.771	18.449	21.528
respite	not increased	19.407 <sup>a</sup>	.752	17.906	20.909
	increased	18.857 <sup>a</sup>	.830	17.199	20.516

Analyses of covariance revealed no significant main effect of group, social activity or dependency on objective burden levels at time 4. In addition, the effect of group on burden did not differ according to changes in social activity or in the level of dependency.

## 2.4 Subjective Carer Stress

Table 11.9 compares subjective stress levels at time 4 (baseline adjusted) between the two study groups by change in social activity, while table 12.10 illustrates the outcome for study group by change in dependency.

**Table 11.9: Subjective stress at time 4 by study group and change in social activity**

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	13.775 <sup>a</sup>	.392	12.992	14.557
	increased	12.357 <sup>a</sup>	.450	11.458	13.256
respite	not increased	13.886 <sup>a</sup>	.505	12.879	14.894
	increased	13.130 <sup>a</sup>	.458	12.214	14.045

**Table 11.10: Subjective stress at time 4 by study group and dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	12.752 <sup>a</sup>	.372	12.009	13.496
	increased	13.379 <sup>a</sup>	.481	12.418	14.341
respite	not increased	13.292 <sup>a</sup>	.449	12.395	14.190
	increased	13.724 <sup>a</sup>	.524	12.677	14.770

As in the case of objective burden, analyses of covariance revealed no significant main effect of group, social activity or dependency on subjective stress levels at time 4. In addition, the effect of group on subjective stress did not differ according to changes in social activity or in the level of dependency.

## 2.5 Subjective Carer Demand

Table 11.11 compares subjective demand levels at time 4 (baseline adjusted) between the two study groups by change in social activity, while table 11.12 illustrates the outcome for study group by change in dependency.

**Table 11.11: Subjective demand at time 4 by study group and change in social activity**

group	Change in activity	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	12.815 <sup>a</sup>	.299	12.217	13.413
	increased	11.838 <sup>a</sup>	.347	11.145	12.531
respite	not increased	12.307 <sup>a</sup>	.391	11.527	13.088
	increased	12.660 <sup>a</sup>	.353	11.955	13.364

**Table 11.12: Subjective demand at time 4 by study group and dependency**

group	Change in dependency	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
control	not increased	12.075 <sup>a</sup>	.286	11.504	12.645
	increased	12.578 <sup>a</sup>	.368	11.842	13.314
respite	not increased	12.472 <sup>a</sup>	.349	11.775	13.169
	increased	12.495 <sup>a</sup>	.404	11.688	13.301

Consistent with the findings for the other carer burden variables, analyses of covariance revealed no significant main effect of group, social activity or dependency on subjective demand levels at time 4. Once again, the effect of

group on subjective demand did not differ according to changes in social activity or in the level of dependency.

## 2.6 Cortisol

As at the previous assessment points, cortisol was examined by time of day point so as to allow the identification of any different effects at each sampling point. Table 11.13 presents the change from baseline to time 4 in cortisol levels by group for 10 am, 2pm, 6pm and 10pm samples.

**Table 11.13: Cortisol at baseline and time 4 by group (spit by sampling time)**

10 am					2pm				
	control		respite			control		respite	
	Mean	Std	Mean	Std		Mean	Std	Mean	Std
baseline	9.74	6.30	8.92	6.00	baseline	6.55	4.71	8.11	4.89
time 4	8.32	5.91	8.98	6.45	time 4	5.99	4.11	6.17	3.65

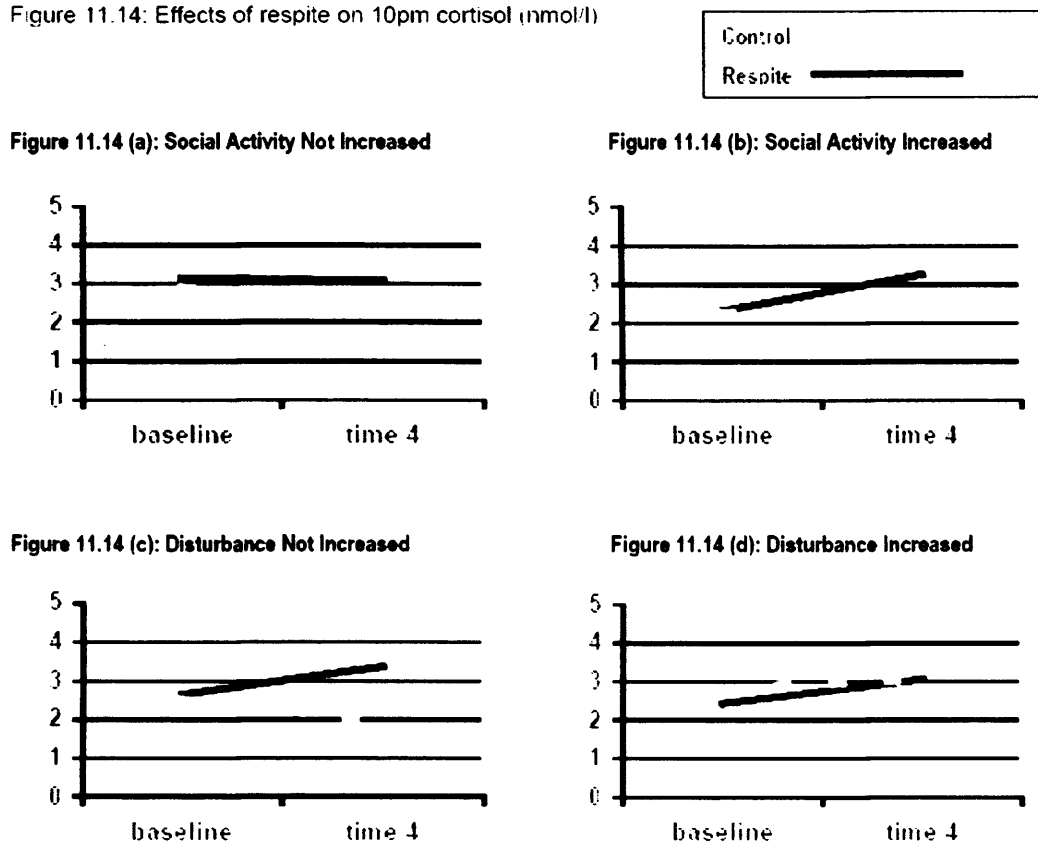
  

6 pm					10 pm				
	control		respite			control		respite	
	Mean	Std	Mean	Std		Mean	Std	Mean	Std
baseline	3.81	2.60	4.97	3.21	baseline	2.67	1.49	2.62	1.48
time 4	2.99	1.80	4.13	2.48	time 4	2.58	1.74	3.27	1.98

Analyses of covariance revealed no significant main effects or interactions on cortisol at time 4 when sampled at 10 am, 2 pm, 6pm and 10pm. However, the effect of group on 10 pm cortisol did vary according to both changes in social activity from baseline to time 2 (see figures 11.14a and 11.14b), and changes in dependency from baseline to time 3 (see figures 11.14c and 11.14d).



Figure 11.14: Effects of respite on 10pm cortisol (nmol/l)



Among those who increased their social activity, respite intervention had the effect of raising 10 pm cortisol at time 4, although no such effect was found among those not increasing their activity ( $F=6.11, df=88, p<0.05$ ). Conversely, among those who reported an increase in dependency, respite intervention had no effect on 10pm cortisol, while among those reporting no increase in dependency, the effect respite intervention was to increase 10 pm cortisol ( $F=6.67, df=88, p<0.05$ ).

### 3 Tests of Mediating Effects

No moderating effects were revealed for either social activity or dependency on most of the outcomes at time 4 (except for 10pm cortisol), tests for mediating effects were still carried out. As in the time 2 and 3 data analyses, mediating

effects were subsequently tested using multiple linear regression. Once again, age, sex and baseline dependency were controlled.

### **3.1 Depression**

In contrast to the time 3 analysis, the results of the multiple regression analysis revealed that respite group accounted for less than 1% of the variance in depression at time 4 after the other variables had been controlled and was therefore not a significant predictor of outcome.

The extent to which changes in social activity and dependency predicted depression at time 4 was also examined. The results indicated that neither social activity or dependency explained a significant amount of the variance in outcome after all other variables had been controlled.

### **3.2 Physical Symptoms**

In relation to physical symptoms at time 4, the results of the multiple regression analysis revealed that the variables did, as a whole, significantly predict outcome, ( $F^{(5,88)} = 25.31, p < 0.001$ ). The total adjusted *R* squared value indicated that 58% of the variance in depression was explained by the model, and that respite group accounted for 5% of the variance after the other variables had been controlled (see table 11.15 for summary of the model). The beta coefficient indicated a lower symptom level in the respite group ( $\beta = -0.24, p < 0.05$ ).

**Table 11.15: Model Summary: Effect of respite on symptoms**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	Sig. F Change
baseline symptoms	.728 <sup>a</sup>	.530	.525	2.90047	.530	97.012	.000
age/sex/disturbance	.747 <sup>b</sup>	.558	.537	2.86381	.028	1.739	.165
respite group	.779 <sup>c</sup>	.607	.583	2.71720	.049	10.198	.002

The extent to which changes in social activity and dependency predicted depression at time 4 was also examined. The results indicated that neither social activity or dependency explained a significant amount of the variance in outcome after all other variables had been controlled.

The extent to which changes in social activity and dependency predicted symptoms at time 4 was also examined. As in the case of depression, the results indicated that dependency did not explain a significant amount of the variance in outcome. However, changes in social activity were associated with physical symptoms, with the regression analysis revealing that it explained 4% of the variance in outcome. An increase in social activity from baseline to time 2 was associated with a decrease in symptoms at time 4 (beta = -0.18,  $p < 0.05$ ).

### 3.3 Objective Carer Burden

In relation to objective burden at time 4, multiple regression analysis revealed that respite group accounted for virtually no variance in outcome after the other variables had been controlled and was not a significant predictor of outcome. The results also indicated that neither social activity or dependency explained a significant amount of the variance in time 4 objective burden after all other variables had been controlled.

### **3.4 Subjective Carer Stress**

Concerning subjective stress levels at time 4, the pattern of results were similar to that found in relation to objective burden. Respite group accounted for just over 1% of the variance in outcome after the other variables had been controlled and was not a significant predictor of outcome. Again, neither social activity or dependency explained a significant amount of the variance in time 4 subjective stress after all other variables had been controlled.

### **3.5 Subjective Carer Demand**

In relation to subjective demand, the results followed that found concerning the other carer burden variables. Respite group accounted for virtually no variance in outcome after the other variables had been controlled and was not a significant predictor of outcome. Neither social activity or dependency explained a significant amount of the variance in time 4 subjective demand.

### **3.6 Cortisol**

For all cortisol sampling times (10 am, 2pm, 6pm and 10pm), multiple regression analyses revealed no association between outcome at time 4 and respite group. As with most of the other variables at this time point, outcome was not predicted by either changes in social activity or by changes in dependency.

#### **4. Summary**

The aim of the analysis at time 4 was again to examine the effect of respite care on outcome, as well as to examine whether this effect differed according to changes in social activity or in dependency. Unlike at time 3, there were no effects of respite group, social activity or dependency on most of the self-report outcomes. The only exception to this pattern was physical symptoms, which were found to be at a significantly lower level for the respite group participants and for those not reporting any increase in dependency. No moderating effects of changes in social activity or dependency were observed.

Concerning cortisol, there were no direct effects of group or either of the third variables on outcome. However, in relation to evening (10pm) cortisol, significant interactions were revealed. Specifically, among those carers who increased their social activity, respite intervention had the effect of raising 10 pm cortisol at time 4 (with no such effect on those not increasing their activity). Conversely, among those who reported an increase in dependency, respite intervention had no effect on 10pm cortisol levels, while among those reporting no increase in dependency, the effect of respite intervention was to increase 10 pm cortisol.

## **Chapter 12: Discussion**

- 1. Summary of findings**
- 2. Support for hypotheses**
- 3. Study Implications: The Aims of Respite**
- 4. Limitations of the study**
- 5. General Conclusions**

## **1. Summary of findings**

The present study set out to examine the short-term effects of residential respite care on a range of outcomes among a sample of spousal carers. The outcomes selected for the evaluation of respite included self-report and direct physiological measures. In conceptual terms, they reflected psychological, social and physical dimensions, and covered end-points that were both generic across the population, and specific to the sub-population of carers.

A sample of 112 carers was recruited into the study at baseline, and a total of 89 were still participating at the final assessment. No significant differences emerged between those participants completing the study and those dropping out.

After controlling for baseline, carers in the respite group exhibited lower levels of all self-report outcomes at time 2 in comparison to controls. Although the effect of respite were moderated by changes in social activity, its effects were not mediated by this factor.

Carers in the respite group also exhibited lower levels of depression and physical symptoms at time 3 in comparison to controls, although the effect of respite on outcome was not moderated or mediated by changes in social activity or dependency. The results did indicate, however, that changes in dependency had a direct effect on outcome, with those reporting an increase in dependency also reported higher levels of depression and physical symptoms at follow up (regardless of study group)

Unlike at time 3, there were no effects of respite group, social activity or dependency on most of the self-report outcomes. The only exception to this

pattern was physical symptoms, which were found to be at a significantly lower level for the respite group participants and for those not reporting any increase in dependency. No moderating effects of changes in social activity or dependency were observed.

## **2. Support for hypotheses**

### **2.1 Effects of participant characteristics on psychological well-being**

Two participant characteristics were of specific interest in the present study: the sex of the carer, and the diagnosis of the care recipient. First, it was predicted that female carers would exhibit poorer psychological well-being than their male counterparts. Second, in view of findings suggesting that it is patients' problematic behaviours that are most closely related to carer well-being, it was hypothesised that carers of people with dementia would exhibit poorer well-being than carers of people with other conditions.

#### **2.1.1 Effect of sex**

The hypothesis that self-reports of depressive symptoms would be higher at baseline among female participants was supported by the data, with the sex of the carer accounting for 10% of the variance in baseline depression levels. This finding is in line with previous work that has consistently revealed higher rates of depression among female carers than among their male counterparts (eg-Cuijpers, 2005).

It has been suggested that gender differences in caregiver depression levels merely reflect generic gender differences in depression related outcomes rather



than caregiving-specific factors (Vitaliano et al. 2003). Studies examining sex differences throughout the entire life span have observed higher rates of depression and depressive symptoms among women, and taken together, findings suggest that the prevalence of depression among women is between one and a half and three times more than the prevalence among men (Brommelhoff et al., 2004). This difference has been explained with reference to the reproductive (eg - oral contraceptives, the luteal phase of the menstrual cycle, the postpartum period, and the menopause) (Parry 2000), as well as to a greater readiness among women to report emotional symptoms than men, who may be more likely to view negative emotional expression as an undesirable weakness (Shaw et al., 1995).

Another view, however, is that that the higher rates of depression among female carers are due to more than simply generic sex differences in depression, and reflect the fact that that women face higher levels of caregiving stressors (eg - Barusch & Spaid, 1989). The gender-role expectation framework (Barusch & Spaid, 1989) proposes that women engage in a more intensive caring role than do men while being less likely to ask for, or be offered, support. They also suggest that female carers are more likely to be dealing with very high levels of care recipient impairment because they are less likely to end their caring role by requesting long term residential care for their relative (Pinquart & Sorensen, 2006).

The findings of the present study, however, do not seem to support the view that sex differences in depression are due to women facing higher levels of caregiving stressors. Analyses revealed that the higher rates of depression observed among women remained significant even after controlling for the age, diagnosis and

illness duration of their care recipient, as well as the reported level of dependency, objective burden and in home / day care support provided.

This finding, however, does not eliminate the possibility that differences in the way in which men and women encounter a caring role has an effect on levels of psychological well-being. It may well be that, since a full-time caring role is more likely to be 'expected' of women than it is of men (Brody, 1981) and that they are more likely to have given up a career to become caregivers (Stone et al., 1989), that male samples of carers include more 'self-selected' carers that were relatively 'ready' for a caring role, while female samples include more 'reluctant' or 'forced' carers. Even given a similar level of caring demands, one would expect a 'forced' and 'reluctant' carer to experience a greater impact of their role on psychological well-being due to the greater likelihood of them feeling cheated or taken for granted.

Another possibility not eliminated by the findings of the present study is that the sex differences in psychological well-being among carers are due to differences in the way men and women cope with the stressors inherent in their role. For example, Ashley & Kleinpeter (2002) found that female caregivers employed more avoidant strategies than did males, which in turn were positively related to levels of depression.

### **2.1.2 Effect of diagnosis**

The second hypothesis, that depressive symptoms would be higher among carers of people with dementia than among carers of people with non-dementia conditions, was not supported. Rather, the factor most closely associated with carer depression was the level of dependency exhibited by the care-recipient.

Although caring for a spouse with dementia was associated with a higher level of behavioural problems, a dementia diagnosis did not predict depression after dependency was controlled.

These findings are consistent with other studies that have found behavioural problems to be a major factor in determining carers well-being (Pornari et al., 2006, Clyburn et al, 2000). They suggest that in studies where carers of dementia sufferers report a greater psychological impact of their role (eg – Rainer et al., 2002), that it is the dependency inherent to a dementia condition that is having the impact on carer well-being rather than the dementia diagnosis per se.

As discussed in earlier chapters, behavioural problems may be particularly closely related to carer well-being for a number of reasons. These include the impact of such problems on carers' sleep patterns and their effect of reducing carers' social contact due to the stigma associated with disruptive behaviour. While sleep patterns were assessed as part of the CAPE-BRS scale in this study, this measure was not administered during respite in the present study (due to the absence of the care-recipient within respite group). The link between dependency and social activity was examined, however, revealing no evidence was found for an association between the two.

## **2.2 Relationships between variables**

Three hypotheses were generated in relation to how the outcome variables in the study may be interrelated. First, it was predicted that self-reports of physical symptoms, depressive symptoms and carer burden would be positively inter-

correlated. Second, the prediction was made that self-reports of physical symptoms, depressive symptoms and carer burden would be positively correlated with reports of social activity. Finally, it was predicted that self-reports of physical symptoms, depressive symptoms and carer burden would be positively correlated with cortisol levels. These hypotheses will now be discussed along with how the results fit with previous, related research findings.

### **2.2.1 Depression, physical symptoms and carer burden**

The hypothesis that self-reports of physical symptoms, depressive symptoms and carer burden would be positively inter-correlated, was generally supported. There was a particularly strong association between reports of depressive and physical symptoms, with over a third of the variance in physical symptom reports explained by levels of depression. This is in line with previous research suggesting that the reporting of physical symptoms is as good a marker of depression as it is of actual physical ill-health (somatising) (Stansfeld et al, 1993).

Carer burden outcomes were generally intercorrelated, but only moderately so. This supports the conceptualisation of burden as a multidimensional phenomena rather than one single concept. Particularly notable in this respect was the lack of association between objective burden and subjective demand. This finding suggests that appraisals by the carer of the care recipient's behaviour should be treated as a separate dimension of carer burden and as distinct from both objective burden and subjective ratings of carer stress (Montgomery et al., 1985).

Concerning the relationship between carer burden and depression, previous findings have been ambivalent. While some studies have suggested that

caregiver burden and depressive symptoms are interrelated and that burden is an antecedent to depressive symptoms (Clyburn et al 2000), others have found that caregiver burden only comes near significance as a predictor of depressive symptoms (Sherwood et al, 2005).

The present study may shed some light on this issue, in that while all of the carer burden variables were positively correlated with depression, only the subjective stress subscale was a significant predictor. As well as going some way to explaining the ambivalent nature of previous findings, this result also lends further support to the value of distinguishing between subjective and objective domains in the study of carer burden.

### **2.2.2 Self-report outcomes and social activity**

The hypothesis that self-reports of physical symptoms, depressive symptoms and carer burden would be negatively correlated with reports of social activity was not supported. While this finding may have been surprising if a subjective operationalisation of social support had been employed (such as perceived support), it may be not be so unexpected in the context of a structural conceptualisation of received support, such as that employed in the present study.

As discussed in earlier chapters, social support has most commonly been assessed in evaluative terms and in relation to its quality given the needs of the individual. As such, a criticism of the (often demonstrated) relationship between social support and well-being is that they are confounded outcomes, and essentially the same construct.

More structural ratings of received support, such as that employed in the current study, may be more conceptually distinct from psychological well-being. Rather than being consistently associated in a negative way with symptoms of poor well-being, received social support may relate both negatively and positively to symptoms of poor well-being at the same time; the combination of which produces a low overall statistical relationship.

A negative relationship between symptoms of poor well-being and received support is likely to result from a 'therapeutic effect' of social contact along the lines traditionally hypothesised in the social support literature (eg – the 'stress buffering' effect proposed by Cohen & Wills, 1985). An opposing, positive association between symptoms of poor well-being and social support may also operate, however, driven by a 'mobilisation effect' (Schwarzer & Leppin, 1991). This effect is determined by the fact that we often seek out support when we feel psychologically or physically 'in need', which are exactly the times when we may also score high on measures of psychological or physical symptoms. Indeed, a social support 'mobilisation effect' could be seen as one explanation of why, in the present study, carers with higher baseline symptoms of depression increased their social activity (from baseline to time 2) more than those reporting a lower level of symptoms at baseline.

In cross-sectional analyses, both the therapeutic and mobilisation effects will rarely be teased out and serve to counterbalance each other in the production of a support – health correlation close to zero.

### **2.2.3 Self-report outcomes and cortisol**

The hypothesis that self-reports of physical and depressive symptoms would be positively correlated with cortisol levels was also unsupported by the data. This may be seen as in some ways contradictory to previous work that has identified high levels of cortisol as a marker for stress (eg – Adam et al. 2006) and depression (eg – Cleare et al., 1995; Jehn et al. 2006)

The present study, however, is not alone in finding a lack of association between self-reports of psychological well-being and cortisol. Cevik et al (2004), for example, observed no significant differences in cortisol levels between patients with high and with low levels of depressive symptoms (as assessed by the Beck Depression Inventory). Similarly, Burke et al. (2005) found no effect of depressive symptoms (as measured by the CES-D) on baseline salivary cortisol levels among a high-risk population of very poor Mexican women. Finally, in a recent study of caregivers, McCallum et al (2006) found no association between cortisol slope over a two-day period and either depression (measured by CES-D) or perceived stress.

One reason for the ambivalent findings in relation to the association between cortisol levels and psychological well-being may lie in the methodology used. In studies that have observed a significant association between psychological well-being and cortisol, psychological well-being has been operationalised in terms of either a) immediate, momentary psychological state (assessed via a diary at the time of cortisol sampling) (eg – Adam, 2006; Adam et al, 2006; Eller et al., 2006; Jacobs et al., 2007), or b) the presence of a chronic clinical affective disorder that is severe and persistent enough to have warranted a diagnosis by a clinician (Cleare et al., 1995; Jehn et al., 2006). In studies that have not found an

association between psychological well-being and cortisol, however, self-report measures of psychological symptoms have been used that ask for retrospective ratings of well-being over a period of several days (such as the CES-D or BDI) (Cevik et al, 2004, McCallum et al, 2006, Ryff et al 2006).

This pattern is supported by the findings of Davis et al., (2004), who employed in situ diaries of stressful events and retrospective ratings of psychological well-being within the same study of caregiver stress. They found that, while diary based ratings of stressful events were closely associated with cortisol levels, caregivers' retrospective ratings of negative affect at the end of a 7-day period were not significantly correlated with cortisol.

Therefore, the lack of association between cortisol and psychological well-being may emerge in studies employing retrospective measures of well-being simply because, although psychological symptoms may indeed have been experienced in the time period tapped into by the questionnaire (eg – 'the last 7 days'), they may not necessary be present at the same level and/or directly affecting endocrine functioning at the time of its assessment.

This is in contrast to studies in which psychological symptoms are either (in the case of diaries) being assessed at the same time as physiological functioning, or (in the case of clinical diagnoses) are severe and persistent enough to be affecting physiological functioning at any time.



## **2.3 Change in dependency**

It has already been reported that the factor most closely associated with carer depression at baseline in the present study was the level of dependency exhibited by the care-recipient. While this finding is consistent with a substantial amount of previous research (eg - Pornari et al., 2006) much less is known about short-term changes in behavioural functioning, either in relation to the antecedents of such changes, or their consequences for carer well-being.

### **2.3.1 Dementia and changes in dependency**

People with dementia function best in a familiar environment. Moving to a new home, rearranging furniture, or even repainting rooms can be disruptive and cause symptoms to worsen (Lawlor, 1997). In the present study, it was predicted that respite care (and the environmental changes inherent in the experience of respite by the care recipient) would exert a negative effect on behavioural function particularly among patients with a diagnosis of dementia.

However, the hypothesis was not supported in that there were no main effects of either study group or diagnosis on changes in dependency (or any interactive effect of the two). This finding is in line with some previous research findings that have also revealed no effect of respite on care recipient's condition (Burdz et al ,1988; Adler et al 1993) and may be seen as a positive finding in respect to carers and those they care for. Importantly, the present study is the first to directly contrast the effects of residential respite on dementia and non-dementia care recipients, and address the possibility that the effect of respite would be different for these groups.

One possibility that can not be wholly eliminated is that respite did exert an effect on condition but that this effect had diminished by the time of the post respite assessment, as found by Neville & Byrne (2006). However, since carers in the present study were asked at the one-week post-respite follow up to rate their partner's condition (retrospectively) across the whole of the previous week, it is likely (although not certain) that such an effect will have been picked up.

The results of present study suggested that, although neither respite intervention or dementia diagnosis influenced changes in behavioural condition over time, that these changes were influenced by the care recipients' initial level of dependency. Specifically, those carers reporting an increase in dependency were those who had rated lower baseline levels of dependency. This is somewhat in line with the findings of Seltzer et al (1988) who reported that that patients with the poorest status tended to show improvement on some measures following respite, while patients with higher initial levels of performance tended to show slight worsening following respite.

This effect may, at least in part, be an example of a regression to the mean. Regression toward the mean refers to the fact that those with extreme scores on any measure at one point in time will, for purely statistical reasons, probably have less extreme scores the next time they are tested.

Importantly, there was no evidence from the present study that effect of initial dependency levels on subsequent changes in dependency differed according to whether or not respite group was received. Rather, low levels of baseline dependency were associated with subsequent increases in dependency in both study groups. Neither was there any evidence of this from Seltzer et al (1988) since their study did not include a 'no respite' control group.

Rather than having anything to do with respite care, the tendency of deteriorations in condition to be more common among those care recipients initially in a better condition at baseline may simply due to the fact that their condition may have been at or near a peak level at the time of the baseline assessment, and thus also having greater potential for deterioration over time.

### **2.3.2 Change in dependency and carer well-being**

Given the evidence for a cross-sectional relationship between dependency and carer well-being, it was predicted in the present study that carers reporting an increase in the behavioural problems in the cared for person in the first fortnight of assessment would report, at follow up, greater levels of depression, physical symptoms and burden than carers reporting no change or a decrease in behavioural problems (after controlling for baseline levels of behavioural problems and outcomes).

The data partially supported the hypothesis in that those carers reporting an increase in dependency also reported higher levels of depression and physical symptoms at time 3 (1 week after respite). There was, however, no effect on carer burden or cortisol outcomes at this time point. At time 4 (3 weeks after respite), the only observed effect of changes in dependency was on physical symptom reports.

These findings serve to confirm the importance to carers' well-being of their care recipients' behavioural condition. However, the findings also take current knowledge one step further, and suggest that changes in dependency impact on well-being even after baseline levels of dependency are controlled. The implication of this is that a care recipient's level dependency, even if it is relatively low compared to that of other patients, can impact on their carer's well-being if it undergoes even a short-term deterioration.

It is possible that changes in behavioural condition may exert their impact on carers because they create uncertainty and give rise to anxieties about the future. A sudden deterioration, even in a patient that is relatively well, may cause the carer to worry about whether the change is a permanent one, and if it is, whether they will still be able to cope with their caring role. In line with this, Pomari et al. (2006) found carers fear of 'incompetence in relation to future caregiving' to be a major predictor of their well-being.

## **2.4 The effects of respite on carers**

The primary aim of the present study was to examine the effects of a residential respite intervention on carers. Two sets of outcomes were of interest; self-reports of well-being, and levels of salivary cortisol. The study set out to examine the strength and stability of any effects of respite, as well as how changes in social activity and dependency may influence these effects.

### **2.4.1 The effects of respite on self-reported well-being**

It was predicted that carers in receipt of respite during the study period would exhibit lower levels of depressive symptoms; physical symptoms and carer burden at follow up than carers not receiving respite care (after controlling for baseline levels in outcome measures).

The hypothesis was partially supported. Overall, the findings of the present study suggested that respite care did exert a significant effect on carer well-being, but in relation to most outcomes, this effect was relatively short-lived:

The stability of the effects of respite varied by the outcome measure used. Regarding carer-specific outcomes (ie- carer burden), the effects of respite were only evident during the break itself. In relation to symptoms of depression, the effects of respite were still evident one week after the end of the break from caring, but not three weeks after. The longest lasting effect of respite was on physical symptoms, which were still lower in the respite group at three-week follow up.

The observation of significant effects at time 2 (during respite) is in line with previous research on the effects of respite care. As in the present study, several

previous investigations have reported improvements in carers' well-being during the respite period itself (eg- Botuck & Winsberg, 1991; Adler et al., 1993; Larkin & Hopcroft, 1993). This effect may seem unsurprising in relation to carer burden outcomes, as these concepts relate largely to contact or dealings with the cared for person, who is of course absent during respite. The effect on depression and physical symptoms is less obvious however, since these concepts are wider than the caring context and may be prone to influence by a wider range of factors. The findings of this study (and others) therefore suggest that respite care (at least during intervention) has an impact upon carers that goes beyond simply relieving the day-to-day stressors inherent to a caring role, and impacts upon well-being in more general and fundamental sense.

The hypothesis that the positive effect of respite on carers' well-being would be greater among carers reporting an increase in their social activity during respite was supported at time 2. The fact that carers who increased their social activity experienced the greatest benefits of the intervention serves to highlight and confirm the importance of social contact to people in a full-time caring role (as also found by Thompson et al., 1993).

However, while social activity was found to moderate the effects of respite at time 2, it was not found to mediate its effects. This distinction is important and means that while the findings tell us something about when or under what conditions respite has a more positive effect, it does not tell us about how or through what mechanisms respite has its effects. The latter conclusion would have required that respite was associated with increased social activity, and that social activity in turn predicted well-being, neither of which were found to be the case.

The present study also found that the effects of respite on depression and physical symptoms were maintained at least one week after the end of the intervention, which again is consistent with the results of previous studies (Botuck & Winsberg, 1991, Caradoc-Davies & Harvey, 1995). The fact that no effect was found at 1 week post-respite on the carer burden variables may be considered unsurprising and consistent with their conceptual proximity and relevance to contact with the cared for person (as discussed above). Since the source of carer burden must inevitably be seen as the impairment and dependence of the care recipient, as well as the perception of these by the carer, it should be no surprise to see carer burden rise when the cared for person re-enters the carer's immediate environment.

The findings of previous research on respite care suggest that its effects do not persist far beyond one week. In studies that have conducted assessments two weeks or more after the end of respite, well-being has been found to return back to baseline levels (eg- Adler et al,1993). These findings were confirmed in the present study, except in the case of physical symptom reports, which remained significantly reduced in the respite group for the entire follow-up period (3 weeks after respite).

One explanation for this finding is that there may be greater stability inherent in physical symptoms than in symptoms of depression. That is, an increase in stress (such as is likely to occur in the first few days after respite) may have more of an immediate effect on affective outcomes than on physical outcomes.

Whatever the explanation, however, this finding represents the first evidence that respite care can have an effect on carers' well-being beyond two weeks. That is

not to say that this finding is contradictory to previous work however. Rather, it is simply the case that the effect emerged on an outcome (physical symptoms) that has never previously been utilised in the evaluation of a single episode of residential respite care.

#### **2.4.2 The effects of respite on cortisol**

The present study was the first to employ salivary cortisol in an evaluation of the effects of respite care, and as an outcome it behaved very differently from the self-reported variables. At time 2 (during respite), and in contrast to the findings for the self-report outcomes, there were no effects of respite on cortisol. Maybe even more surprisingly, while there was a significant effect on (10 am) cortisol levels at time 3 (1 week after respite), this effect was the reverse of that found for self-reported outcomes. That is, cortisol was actually higher among the respite group than among controls.

It could be argued that these findings reflect the fact that cortisol was found in the present study (and in previous research) to be unrelated to outcomes such as depression and physical symptoms (see section 2.2.3 above). While cortisol reflects an individual's immediate state of activation, the self-report outcomes are more retrospective and tap into a wider period of experience (eg – over the last 7 days).

The distinction between momentary activation and retrospective reports of well-being may be crucial to explaining why cortisol levels did not fall at time 2, during the respite period. For carers, respite is not simply a chance for rest. The break from caring also provides a much-needed opportunity for carers to attend to other



tasks and chores that they were not able to attend to while the care recipient was at home. For example, carers in Levin et al.'s (1989, 1994) studies reported using the respite break to spring clean or decorate.

These tasks may have previously weighed on the carer's mind and been a source of anxiety. Hence, finally having the chance to deal with them is likely to have a subsequent positive effect on psychological well-being (manifested in improved ratings of well-being on retrospective measures). However, the carer's actual engagement in dealing with tasks such as work on the home would, at the time, have been likely to involve a high level of engagement and even stress. This, in turn, would have been likely to elevate cortisol levels (Klumb et al., 2006), and result in any attenuating effects of respite on cortisol being obscured.

The fact that elevated levels of cortisol were found in the respite group at time 3 (1 week after respite) may, like the lack of effect at time 2, also be considered surprising. This is especially true when we consider that cortisol is traditionally seen as a marker for stress and that, at time 3, respite group carers exhibited improved psychological well-being and physical symptoms.

However, this pattern can also be explained if we consider the likely experiences of carers at this time. The return of the care recipient to the home is inevitably a time of adjustment for the carer, and involves a sudden (albeit expected) change in demands and daily routine. This change in routine and demands, in turn, will be likely to have an impact on cortisol levels just as it has been demonstrated to do in shift-workers changing from one shift pattern to another (Kudielka et al. 2007). Therefore, it is feasible that, at the time 3 assessments, respite group participants were able to feel the psychological benefit of their recent break from

caring while simultaneously undergoing a period of physiological activation and adjustment.

Complex effects on evening (10pm) cortisol were observed at time 4 (3 weeks after respite). Levels were raised among respite group carers who had a) experienced an increase in social activity during respite and b) those who had not observed an increase in their care recipient's dependency on their return from respite. Taken together, carers falling into these groups would have presumably enjoyed respite more than those who had not been socially active or who did observe deterioration in behavioural condition.

It is plausible that, for these carers, a 3-week period back in a full-time caring role had presented a stark contrast between their life as a carer and the positive 'normal life' experience that the respite week(s) had allowed them. Unlike at 1 week post-respite, when all respite group carers were still adjusting to the caring situation, the three-week stage may be a point at which those who had the most positive experience during respite must undergo more psychological adjustment.

While this adjustment would be unlikely to be severe or prolonged enough to manifest itself in terms of depression or physical symptoms, it may have been sufficient to elevate evening cortisol levels when, after the caring day, the carer had time to consider the contrast in experiences. This interpretation is, of course, speculative and cannot be confirmed by the data in the present study.

Whatever the explanations for the effects on cortisol, however, the fact that these effects should only be evident in morning and evening cortisol levels is fairly consistent with previous research. As discussed in earlier chapters, in situations

of chronic stress, it may be morning and evening cortisol levels that are the most revealing (eg - Vedhara et al.,1999; Ockenfels et al. 1995). For example, the finding that carers soon after receiving their care recipient back into the home had elevated morning cortisol levels rather than elevated levels at any other time makes sense if we consider that mornings are one of the most stressful times of the day for carers (requiring tasks such as getting the care recipient out of bed, washing, breakfast and often, getting them ready for day care).

### **3. Study Implications: The Aims of Respite**

In chapter 2, the National Strategy for Carers (DH, 1999) was referenced and some main 'aims of respite' were derived from its key statements. These were summarised as follows:

- a) Reducing the impact of the caring role on carers' well-being
- b) Allowing carers to maintain their 'social' life outside of the caring role
- c) To avoid any detrimental effects of carer support intervention on the cared for person
- d) To preserve the informal caring relationship over time.

The implications of the present study's findings in relation to these aims are examined below along with what they mean for future policy and / or research.

#### **3.1 Reducing the impact of the caring role on carers' well-being**

Maybe the main implication of the findings of this study is that a single episode of residential respite care does indeed have a measurable and positive effect on carer well-being. For many, especially those involved in caregiver support, this is

simply indicative of something that they already know, and will serve as confirmation that respite is valuable tool in the alleviation of caregiver burden and something that should be financially supported (Carers UK, 2004).

There are of course degrees of 'value'. Indeed, it could be argued that the fact respite provides temporary relief to carers during its provision is rather obvious, and not something that carers can build on and benefit from in the long term (such as may be the case with skills training interventions or the provision of supportive contacts).

Therefore, it is very significant that the present study also observed an effect of respite after the break from caring had come to an end. This is important if we see the purpose of respite intervention as having a 'healing' effect rather than simply a 'relieving' effect. That is to say, an observable effect of respite beyond its duration is essential if we see its purpose as reversing some of the damage done to the carer by their stressful role and leaving them better able to cope in the future.

An analogy can be drawn here with the application of a plaster cast to a broken arm. If the cast only provides support and protects from pain while it is in place on the arm, then it is of very limited value. If, however, it also allows healing to take place and its beneficial effects go on beyond the point at which it is removed, then its value can be placed at a higher level. The findings of the present study suggests that respite not only provides relief and support during intervention, but also allows some healing to take place and leaves the carer in an improved state of well-being even after the intervention has ended. This in turn may leave the carer better able to cope with their caring role.

The implications of the present study in relation to exactly how long these healing effects persist are rather mixed. While the effects on depressive symptoms were found to diminish somewhere between one and three weeks after respite had ended, the effects on physical symptom reports (themselves a likely indicator of psychological well-being) were evident for the entire study period. This is the first evidence of an effect of respite beyond 2 weeks (as well as the first evidence of an effect on this outcome) and therefore positive. However, the short-lived nature of the effects on depression still hints at the possibility that respite can only improve well-being for a very limited time.

To evaluate the value of respite purely in terms of its ability to *improve* well-being is arguably, however, over-stringent. The value of an intervention aimed at a section of society prone to declining health status should surely also be evaluated in terms of its ability to *maintain* well-being and prevent deterioration. While the present study can offer no direct evidence of a long-term maintenance effect on well-being, the fact that a short-term improvement was observed would suggest that long-term maintenance of well-being would be likely if the intervention were to be repeated regularly. Indeed, the positive effects of long-term programmes of respite have been demonstrated in previous research (Lawton et al. 1989; Montgomery & Borgotta 1989).

One other potentially important finding from the present study was that there was no correlation found between the length of respite and either baseline outcomes or changes in outcomes across the study period. Although the natural assumption may be that longer respite periods will equal more gains in well-being, this data suggest that there is no simple, linear relationship. Alternatively, it may

be that an optimum length of respite may exist for each carer after which gains in well-being plateau or even decline, possibly because very long respite periods leave the carer 'missing' the care recipient. This is a matter for future research.

### **3.2 Allowing carers to maintain their 'social' life**

Given the wealth of literature pointing to a positive association between social support and well-being, it is no surprise that one of the stated aims of respite has been to provide carers with an opportunity for social contact. The implications of the present study are that, while the immediate effects of respite are at their most beneficial when social activity does increase, the provision of respite per se does not increase social activity to any significant extent.

There may be several reasons for this. First, carers may often have other priorities during respite and may see social contact as a luxury only to be afforded after the tasks have been achieved. As already discussed, it is inevitable when one is engaged in a full-time caring role that other items on an individual's 'agenda' (eg – home improvements, managing financial or legal affairs) will not be attended to. Therefore, respite may, in many cases, be devoted to catching up with such tasks, leaving little time for socialisation. Future evaluations of respite care may possibly include evaluations of activity during respite to examine the extent to which this is a feature of respite and how it influences outcome.

Another reason for the failure of respite care to increase social activity may simply be that there are few people left in carers' lives to have social contact with. Evidence was presented in earlier chapters to suggest that carers are very prone

to social isolation (Miller & Montgomery, 1990). This may well be relevant to the experience of respite care. For example, Nicoll et al.(2002) found satisfaction with respite care to be correlated significantly with the numbers of people in carers' social network. Future evaluations of respite may also, therefore, be able to examine the influence of social isolation on the effects of respite care.

If carers are unable to increase their social activity during respite then there may be a case for interventions aimed at increasing social activity running alongside respite provision. The nature of these interventions may, in part, be driven by the reasons why particular carers find increasing their social activity during respite problematic. If it is for the first reason mentioned above, that is, because of other competing demands on the carers' time, then the answer may be to provide support and assistance in these areas to reduce their impact on the respite period (eg – providing transport during respite or help with home improvements). If, however, increasing social activity is problematic because of a lack of social contacts, then the answer may be to focus on 'grafting on' new social supportive ties. Such interventions may take the form of a one-to-one 'buddy' programme, or through organisation of group based activities.

### **3.3 To avoid detrimental effects on the cared for person**

It has been estimated that over 60% of carers see significant barriers against using respite care, and one of the most prevalent is a sense of unfamiliarity and conflict over the appropriateness of respite for their care recipient (Rakowski & Clark, 1985). Carers often have fears about the effects respite may have on their care recipient and, because of this, feelings of guilt often go hand in hand with accessing this form of support.

The implication of the present study is that respite does not inevitably have a negative on care recipients, at least as in relation to changes in dependency over the respite period. While there is a question of how representative the experiences of respite in the present study actually were (a methodological issue discussed more fully later) this finding may suggest that some reassurance to carers about the effects of respite on their care recipients may be appropriate. In particular, while the assumption may often be made that residential respite care will have a more negative impact upon those with a diagnosis of dementia than for those with other conditions (due to the documented effects of new surroundings on people with dementia (McGilton et al. 2003), there was no evidence of this in the findings of the present study.

### **3.4 To preserve the informal caring relationship over time**

A final aim of the provision of respite care is to enable carers to continue in their caring role and avoid, for as long as possible, the permanent placement of the care recipient in long-term residential care. While the findings did indicate that respite can alleviate burden, and previous work suggests that the decision to end caring is largely influenced by the level of carer burden experienced (Zarit et al., 1986), the design of the present study does not allow for any direct evaluation of the impact of respite on the likelihood that a carer will continue in their role. Evidence from previous studies is mixed, with some reporting that respite prolongs the informal caring role (Kosloski & Montgomery 1995) and others implying that respite actually encourages permanent placement (Larkin & Hopcroft, 1993).

It may well be that providing interventions with the aim of prolonging the caring role is as much one driven by the needs of society and the scarcity of national



resources as it is one derived from compassion for carers and care recipients. Indeed, it may be argued that to include time to permanent placement as an 'outcome' of carer support intervention is unethical, as the assumption that such placement is not entirely appropriate and in the interests of both carer and care recipient will often be a false one.

### **3.5 Carers' evaluations of respite**

The data from the respite evaluation scale that was administered to the respite group participants at time 3 goes some way to confirming the validity of the distinction between the aims of respite identified above. The responses given by carers indicated that, although in most cases interrelated, the carer effects of respite, the care-recipient effects of respite, and the functions of respite are fairly distinct ways in which carers may evaluate the respite care services provided to them. The fact that this scale had a clear factor structure and excellent internal reliability, as well as the finding that the carer effects of respite were associated with changes in depression levels, suggests that the instrument may prove useful in future studies of respite care.

A notable finding was that, while carers gave fairly high ratings on all three subscales of the respite evaluation scale, the lowest ratings emerged on the care recipient effects subscale. It can of course be argued that such ratings are unimportant given the evidence in the present study that respite does not lead to any detriment in care recipient condition, even in the case of those with dementia. Indeed, one may question why we need carer evaluations of respite when we have standardised instruments to measure outcomes in relation to carer and care recipient well-being.

This argument misses a very important point however. Only a small proportion of those carers who are eligible make use of respite services (Chappell et al., 2002), and as Arskey et al (2004) found in their review of respite services, carers views of the standards and quality of the care provided to their care recipient greatly influence service uptake. If carers fear that care recipients will return home in a worse state, this will lead them to experience guilt in using respite services in order to take a break, and discourage the use of this form of support.

One important question raised by the findings of the present study is why, in relation to the effects of respite on the carer, carers of someone with dementia evaluated the respite period more positively than carers of those without dementia. Notably, this finding remained significant after the level of care recipient dependency had been controlled, suggesting that it was something about the diagnosis rather than the actual condition of the care recipient that was having an effect.

One explanation may be that a diagnosis of dementia is perhaps more likely to lead to a person being referred to a respite service with specially trained staff (eg – that can recognise symptoms and side effects, and have a knowledge of the range of conditions that could cause dementia) and appropriate resources (eg - high user/staff ratios and systems in place to help with orientation). If this explanation were true, however, then one would also have expected to see a higher rating from this group on the care recipient effects subscale too. However, this did not emerge.

Another explanation for the higher ratings among dementia carers on the carer effects subscale may simply have been that dementia carers are under a greater

level of demand in their caring role and therefore feel the beneficial effects of respite more than non-dementia carers. This theory is supported by the fact that dementia sufferers in the present study were rated by their carers as exhibiting a higher level of dependency at baseline, which in turn was closely related to carer well-being.

Unfortunately, the question of whether dementia carers benefited more from respite than non-dementia carers could not be directly answered due a lack of statistical power. Specifically, while the respite group (on which the respite evaluation scale analyses were based) was evenly balanced between dementia and non-dementia carers ( $n= 25$  and  $28$  respectively), the control group only contained  $13$  dementia carers (versus  $40$  non-dementia carers). In a  $2 \times 2$  (group  $\times$  diagnosis) model, this would have left the 'control group / dementia carer' cell under-represented and power unacceptably low. Future research with sufficient dementia and non-dementia carers in both study groups may be able to examine the effect of diagnosis on respite outcome.

One final consideration of the findings relation to the carers' respite evaluations is whether or not they are synonymous with 'satisfaction'. For example, if a carer assigns a low score to the item relating to whether they felt their care recipient enjoyed respite, does this necessarily mean that this detracted from their satisfaction with the intervention? Rather, it is likely that while the Carer Evaluation Scale provides information on the effects of respite as perceived by carers, it tell us little about what those perceived effects mean for the carer and to what extent their needs are satisfied.

#### **4. Limitations of the study**

The conclusions drawn from the present study must be evaluated within the context of certain study limitations. These are discussed below in relation to the design of the study, the sample used, the outcome measures employed and the statistical tests performed.

##### **4.1 Allocation to groups**

In the present study, the way in which carers were allocated to either the respite or control groups could be described as opportunistic. That is to say, it was based upon whether or not they had a respite period scheduled in the next two months.

It can be argued that this method of group allocation, as with any method that is not entirely random, can result in a bias. It is possible that some factor or factors that may influence group allocation may also influence outcome, and reduce the extent to which any differences between the groups at follow up may be attributed to the intervention.

In the present study, random allocation to groups was not carried out for a number of pragmatic and ethical reasons (see methods chapter). While these reasons may be valid, they do not diminish the potential for a bias in group allocation and this must be taken into account when interpreting the findings.

Baseline tests were employed to compare the study groups on all potentially confounding variables. Only one factor was found to be both different between the groups and be associated with outcome (the level of care recipient dependency). This factor was subsequently controlled for as a covariate in analyses so as to account for its effects.

Despite this, however, the possibility that other, unknown factors may have existed that both operated on group allocation and influenced outcome cannot be discounted. Only a fully randomised controlled trial in which all factors (known and unknown) are (in theory) evenly distributed across groups can achieve this equality of groups.

Another limitation related to the decision to evaluate existing intervention delivery rather than randomly allocate to a bespoke respite intervention was the consequential lack of control over the care provided. While this can be seen as more of a 'real world' approach to the evaluation of respite, there is no guarantee that the respite care provided to the study participants was representative of respite care in the UK or even the south-east England region.

A lack of control over the intervention also prevented any analysis of how various elements of respite, and how they are delivered, may affect outcome. In future research, a bespoke intervention would allow the research team to manipulate and isolate the effects of different care elements (egg – the provision of certain therapeutic activities or number of visits by the carer). This, in turn, would directly inform service improvements and enhance benefits to carers and / or care recipients.

## **4.2 The sample**

The study employed a sample of full-time carers all looking after a chronically spouse at home. Questions can be raised, however, about how appropriate the final sample was, both in relation to how representative it was of the carer population, and in relation to its size.

#### **4.2.1 A Representative Sample?**

A sample can only be said to represent the entire population when it closely matches the characteristics of that population. When a sample falls short in relation to how representative it is, the extent to one may generalise the study findings is limited. There are a number of issues that may reduce the extent to which the sample utilised in the present study may be said to be representative of the population of informal carers.

First, the sample was made up entirely of those caring for a spouse or partner. Therefore, the results of the present study cannot be generalised with any confidence to other carers, such as those of chronically ill children or parents. This restriction was deliberate, because as discussed in the first chapter and the methods chapter, the experience of caring, and therefore maybe the effects of interventions, are likely to vary across different kin-ship relationships. If respite has a differential impact for, say, carers of spouses and for carers of parents, then the practice of 'mixing up' these groups within the same design would possibly have led to effects being obscured. The solution, of course, is to include sufficient numbers of all the different types of relationship so as to allow comparisons. This, however, would require a very large sample size and one that would have been beyond the financial and time resources available in the present study.

Second, the method of recruiting carers into the study via carer support organisations may reduce the extent to which the findings may be generalised. As discussed in an earlier chapter, the method of recruiting carers from the lists of support organisations may potentially create a sampling bias. On the one hand, the sample may have over represented those carers under the highest level of

demands since many members of carer support organisations are those that have felt (at least at some point in time) that they needed external help and support. On the other hand, it can be argued that the continuing membership and the support from an organisation is likely to alleviate burden, thus creating a bias towards the less distressed and isolated carers within the population. While it can be argued that any sampling method has inherent bias (in that only those with a certain level of motivation and well-being will be willing to take part in a study), future work should endeavour to make use of means of contacting carers that have become available since the present study was begun and that have maybe less potential for biasing a sample (eg. GP records of carers).

Third, there can be no doubt that carers belonging to ethnic minorities were wholly under-represented in the present study. There may be a number of reasons for this, including the fact that English was the only language available to the research team, and possibly that carers from ethnic minorities have lower levels of community support receipt, both in terms of belonging to carer support organisations, and in relation to access to respite care. This latter reason for the lack of black and ethnic minority carers in the present study is exactly why there is a need for future research into informal caring to deliberately target these groups. In a Social Services Inspectorate study of community care services for black and minority ethnic older people (SSI, 1998), it was found that these groups are likely to suffer significant disadvantage in gaining access to community care services due to culturally inappropriate service provision, a lack of accessible information on the help available (in appropriate languages) and because of a lack of staff skilled in anti-discriminatory practice and cultural sensitivity.

Finally, the extent to which any sample is representative may be indicated to some degree by the response rate, that is, the proportion of individuals invited to take part in the study that actually take up the invitation and participate. The response rate in relation to the present study is unknown as recruitment was largely via advertisements in carer support centres and publications. It can be argued that, since participation in the study involved four fairly lengthy interviews (as well as saliva sampling), the response rate would have been low and participating carers may have been those with more time on their hands and possibly a lower level of demands than the population of carers as a whole.

#### **4.2.2 Sample size**

The study was ambitious in that it attempted to examine not just the effects of respite, but also how this effect may be moderated or mediated by other independent variables. While this use of additional factors was important in order to shed more light on the issues of when or how respite exerts its effects, it would have had the effect of raising the required sample size and reducing the overall statistical power of the study.

It is likely that the sample in the present study was not large enough so as to be able to confidently reject the null hypothesis in all cases. Type II errors may have been particularly likely at time four, by which time 23 participants had been lost from the sample, and when far fewer significant effects of respite were detected.

One way in which the sample may have been particularly deficient may have been in relation to the number of carers with a care recipient suffering from dementia. As already discussed in the section on the respite evaluation scale, only a third of the sample were caring for someone with dementia, and only 13 of these were in



the control group. The low sample size in the 'control group / dementia carer' cell made a 2x2 (group x diagnosis) analysis impossible.

#### **4.2.3 Care Recipient Diagnosis**

In the present study, the diagnosis of the care recipient was sought from the carer. This was done from a number of reasons, which are outlined in the methods chapter, and included unwillingness on the part of many carers to participate in the study in the presence of their care recipient.

This method of confirming a diagnosis is arguably inexact however. Dementia, for example, is not a simple diagnosis to arrive at, and may include time spent gathering details of the family history, information on the development and progression of symptoms, physical examinations and neuropsychological testing. Despite this, compared to many other medical conditions, the concept of dementia it is relatively engrained in our culture. Like in the case of many other conditions, there is both a clinical and lay meaning. There is the danger, therefore, that someone (especially someone of advanced years) who has exhibited cognitive or behavioural problems may be attributed the label 'dementia' by a family member (or even a professional) without this actually having been appropriately confirmed. The method in the present study of confirming care recipients' diagnosis via the carer would not have excluded this possibility, and 'false positives' in respect to a dementia diagnosis may have occurred.

Ironically, the 'popularisation' of dementia as a concept may also have increased the danger of 'false negatives' in the present study. Dementia is a diagnosis that can carry negative connotations, and one that can provoke negative responses in

others. A diagnosis of dementia may add to the already considerable stigma felt by carers who may therefore adopt the practice of describing their spouse or partner's condition in some other way. The possibility of this occurring in the present study cannot be discounted.

Another limitation in the approach taken by the present study to the diagnosis of dementia is that it was arguably too simplistic. The word dementia is an overall term that covers several conditions, including Alzheimer's Disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies. These conditions, while obviously sharing common factors, can vary according to their history, symptoms, and maybe most importantly, the experience they present to both the patient and those who care for them. Future studies, with sufficient numbers of participants, may be able to examine the differential effects of respite on carers and care recipients living with different forms of dementia and indeed other illnesses.

Related to this issue of an over simplistic view of dementia is that the hypotheses in the present study have been criticised for taking an over simplistic view of the consequences of dementia in comparison to other conditions. The fact that a large proportion of carers in the study were engaged in looking after a partner without dementia suggest that behavioural problems are by no means limited to dementia related conditions and can in fact emerge within the context of many chronic conditions.

#### **4.3 Outcome measures**

A range of instruments and techniques were employed to measure outcome and third variables in the present study. The majority of these have been widely used

and have been shown to have acceptable levels of reliability and validity. There were some limitations in relation to outcome measurement however, which are discussed below.

Instruments designed to assess carer burden have been criticised for their lack of sensitivity to change and a tendency to produce ceiling effects (Zarit & Toseland, 1989). In an attempt to maximise sensitivity to change in the present study, the Caregiver Burden Scale was adapted to allow carers to indicate a perception of change from a 'normal' level. That is, instead of rating their level of burden in the original absolute sense (eg- 'not at all' to 'a great deal') carers were asked to rate their burden (in the last week) as to whether it had been 'a lot less than usual' to 'a lot more than usual'.

Analysis of the data revealed that, while the new scale had some concurrent validity and internal reliability, one subscale (subjective demand) had poor external reliability as evident in a low test-retest correlation. While a measure of burden that has too high a test-retest correlation is likely to be insensitive to change and be measuring trait-like constructs, one still requires a certain level of reliability over time to be confident that a measure is useful.

Given the lack of variance in follow up levels of carer burden that were predicted by baseline levels of burden, it is arguable that the results of the study pertaining to this concept (and particularly subjective carer demand) should be treated with caution.

Another new measure used in the present study was that of social activity. No instrument was found among previously published work that was suitable for

assessing changes in levels of social activity from one time to another. Therefore, a 12-item checklist of social events was developed that asked participants to estimate the number of times they had engaged in each activity listed in the last seven days. In contrast to the adapted carer burden instrument, while the data over the study period indicated that the social activity checklist had good external reliability, internal reliability fell short of conventionally acceptable levels. The implication of this is was that the items on the checklist were not governed by one underlying factor. It can be argued, however, that a checklist based measure, rather than other types of instruments measuring attitudes or personality traits, may not require all items to be highly intercorrelated. It is perfectly feasible that social activity in one area (eg – telephone based) may rise while activity in another area does not (eg – face to face contact with friends).

Other limitations of the present study relate not to the measures that were used, but to the measures that were not used. Possibly the most notable study omission from this evaluation of respite of a Quality of Life Scale.

There are a number of reasons why this omission can be justified. First, quality of life can be seen as a wide-ranging and inconsistently defined concept. As Carr et al (1996) point out – it has been equated in previous research with a variety of terms, including life satisfaction, self esteem, well-being, happiness, health, the value of life and functional status.

Such a wide-ranging conceptual basis has also led to some degree of imprecision in measurement. For example, The SF-36, the quality of life measure that has gained much popularity over recent years, measures subjective health status on eight dimensions using relatively few items. These include physical function, role

limitations, social function, mental health, energy/vitality, pain, health perceptions and change in health. Carr et al (1996) suggest that the trade-off for this brevity and comprehensiveness is the loss of detailed information. This, in turn, makes the instrument susceptible to floor and ceiling effects (e.g. the physical functioning subscale includes only one item focusing on daily self-care activities). Loss of precision may be acceptable in large-scale population surveys, but not in intervention studies where such measurement error may obscure clinically important change.

Despite these limitations, however, there has been a growing interest in the concept of quality of life among carers. This has included examining the definitions of the concept of caregiver quality of life, examining caregiver goals and burdens, identifying factors that could contribute to or impact the Quality of Life of caregivers, and the development of instruments specifically designed to assess quality of life in the caregiver population (see Glozman 2004 for review).

In the light of this work, future research on respite may benefit from attempting to extend evaluations of its effects to the concept quality of life while paying attention to the potential for obscured effects and over inclusive conceptualisation.

Another limitation of the present study in relation to outcome measurement in the present study concerns cortisol. The present study was the first to utilise cortisol outcomes in examining the effects of respite care. Samples were taken by carers in situ across a whole day (at 10 am, 2pm, 6 pm, 10pm). However, an omission from the study was some assessment of waking time or cortisol levels at wakening. Changes in care recipient dependency; psychological well-being and the provision of respite may have all affected carers' sleep patterns and time of

waking. In turn, the time of waking is likely to have had an effect on cortisol, since it is a hormone whose production is controlled by a circadian rhythm. In retrospect, analyses of cortisol levels should have controlled for the time of waking and also possibly included assessments of waking cortisol which have themselves been shown to be related to levels of stress (eg - Kunz-Ebrecht et al., 2004).

Another potential limitation in relation to measures concerns the CAPE-BRS assessments of care recipient dependency. While the high correlation between dependency at times 1 and 3 (0.84) suggests test-retest reliability – it may also indicate limited sensitivity to change. The consequence of this may have been an obscuring of the more subtle effects of respite on care recipients (both positive and negative).

The lack of sensitivity to change in CAPE-BRS scores may have resulted for at least two reasons. First, the items in the scale may miss areas of functioning that are sensitive to respite care (eg – some aspects of affective state). Second, the timing of the first follow up assessment (one week post respite) may have been too late to pick up on any immediate but transitory effects of intervention.

Finally, a general limitation of the outcomes utilised in the present study was the exclusive reliance on a quantitative approach. While numerical data is useful for gauging effects and trends, this approach limits the extent to which meaning can be derived from findings.

Maybe most notably, the outcomes utilised in the study did not facilitate analysis of the 'meanings' of respite held by the participants. As discussed in the

introductory chapter, previous qualitative work has found that carer's understanding and use of the term 'respite' differed to that set out by policy makers (Chappell et al. 2001). When asked what having a break meant to them, two main themes emerged. These were '*Internal respite*' and '*External respite*'.

To some extent, both concepts were addressed in the present study. The main hypotheses around the effects of intervention were relevant the 'external' dimension of respite (absolute physical and mental relief from caring, or an opportunity to see friends and relatives outside of the caring role) while 'internal respite' ( 'stolen moments' or periods when the care recipient is relatively happy or comfortable thus providing a break from the condition) are relevant to the association observed between changes in care recipient condition and carer well-being.

However, the lack of a qualitative approach in the present study did not allow any evaluation of the 'meanings' carers hold in relation to these concepts of respite and the value attached to each. Subsequent research may benefit from extending respite evaluations to include these concepts – preferably attempting to gauge meaning as well as trends through a combination of quantitative and qualitative approaches.

#### **4.4 Statistical Methods**

The approach to statistical analysis in the present study reflected the comprehensive approach adopted in assessing the effects of respite. Several outcomes were included in the study, as well as multiple independent variables. This inevitably led to numerous statistical tests being required, which (as

mentioned in the methods section) increases the probability that significant results would be found purely due to chance.

A reduction in alpha, possibly based upon a Bonferroni procedure, may have addressed this issue. However, a serious problem associated with the Bonferroni procedure is a substantial reduction in power and an elevation in the chances of making a type II error (Jennions and Møller, 2003) and in the majority of work in the behavioural sciences, bonferroni corrections leave statistical power unacceptably low according to Nakagawa (2004). This is particularly the case in studies that are measuring numerous outcomes and / or are interested in the interactive effect between factors. What is more, the attrition in sample size over the study period is likely to have left the study rather underpowered, particularly in relation to interactive effects. Any further reduction in power by reduction in alpha may have obscured findings to an unacceptable degree.

Despite this, however, numerous tests were nevertheless carried out and it is possible that some findings represent a type I error. Future work on the effects of respite may be able to include larger samples that would give a study sufficient power for reducing alpha and enable conclusions to be made with more confidence.

## **5. General Conclusions**

Despite several limitations, the present study has gone some way to advance current knowledge in relation to respite care. Maybe most notably, it has provided the first evidence that respite care can an effect on carers beyond 2 weeks after its end, as well as the first evidence of an effect of respite on carers' experience of



physical symptoms. Second, the study has also demonstrated that respite has a more positive impact upon carers when they are able to increase their social activity during the respite period, although it also indicated that increased social activity is not a 'product' of respite and its provision does not necessarily affect social activity to any significant degree. Third, the findings have confirmed that changes in care recipients' level of dependency impact immediately and significantly upon carers' well-being, although they also suggest that respite does not necessarily have an effect on dependency, even among those with a diagnosis of dementia. Fourth, the present study was the first to include cortisol as an outcome in the evaluation of respite, and indicated that the physiological effects of respite can, for reasons yet to be fully understood, contrast with the effects on retrospective self-reports of well-being by carers. Finally, the study included the development of a respite evaluation scale, which has a clear factor structure, good internal reliability and some predictive validity. This scale may prove useful in future studies of respite care.

Respite is important. That is not to say that its effects are consistently positive or welcome to carers, or that it always meets its aims. But it is important to carers in that it provides a break in which carers can find relief and which at least some healing can take place. Future work may be able to say more about both when and how respite has the most benefit for carers and care recipients, and what interventions may run alongside it to enhance and, in particular, prolong these benefits. In the meantime, the findings of this study suggest that ongoing funding in its regular provision may be well worthwhile.

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## **Appendix 1: Measures Used in The Study**

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week by circling the appropriate response.

**1. I was bothered by things that usually don't bother me.**

Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)
---	--	--	---------------------------------------

**2. I did not feel like eating; my appetite was poor.**

Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)
---	--	--	---------------------------------------

**3. I felt that I could not shake off the blues even with help from my family or friends.**

Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)
---	--	--	---------------------------------------

**4. I felt that I was just as good as other people.**

Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)
---	--	--	---------------------------------------

**5. I had trouble keeping my mind on what I was doing.**

Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)
---	--	--	---------------------------------------

**6. I felt depressed.**

Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)
---	--	--	---------------------------------------

7. I felt that everything I did was an effort.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

8. I felt hopeful about the future.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

9. I thought my life had been a failure.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

10. I felt fearful.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

11. My sleep was restless.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

12. I was happy.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

13. I talked less than usual.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)



14. I felt lonely.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

15. People were unfriendly.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

16. I enjoyed life.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

17. I had crying spells.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

18. I felt sad.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

19. I felt that people disliked me.			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

20. I could not get "going."			
Rarely or none of the time (Less than 1 day)	Some of a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 days)	Most or All of the Time (5-7 days)

Have you had any of the following symptoms in the last week? (circle yes or no)

- |  |       |    |
|--|-------|----|
| a) A cough, catarrh or phlegm                                | Yes   | No |
| b) Diarrhoea   | Yes   | No |
| c) Heartburn, wind or indigestion                            | Yes   | No |
| d) Shortness of breath                                       | Yes   | No |
| e) Dizziness or giddiness                                    | Yes   | No |
| f) Earache or discomfort in the ears                         | Yes   | No |
| g) Swollen Ankles  | Yes   | No |
| h) Nervy, tense or depressed                                 | Yes   | No |
| i) A cold or flu   | Yes   | No |
| j) A sore throat   | Yes   | No |
| k) Difficulty in sleeping                                    | Yes   | No |
| l) Pains in the chest  | Yes   | No |
| m) A backache or pains in the back                           | Yes   | No |
| n) Nausea or vomiting  | Yes   | No |
| o) Feeling tired for no apparent reason                      | Yes   | No |
| p) Rashes, itches or other skin trouble                      | Yes   | No |
| q) Blocked or runny nose                                     | Yes   | No |
| r) Dry throat  | Yes   | No |
| s) Headache  | Yes   | No |
| t) Dry, itchy or tired eyes                                  | Yes   | No |
| u) Wheeziness  | Yes   | No |
| v) Toothache or trouble with the gums                        | Yes   | No |
| w) Any other complaints in the last 7 days (Please specify): | _____ |    |

We are interested in how much (if at all) your life has been different from normal over the past week. Please rate the extent to which the following aspects of your life have been different from what is usually the case for you.

Over the past week, has the time to yourself been... (circle one)

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
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Over the past week, has the stress in your relationship with your relative been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
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Over the past week, has your personal privacy been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, have the attempts by your relative to manipulate you been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, has your time to spend in recreational activities been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, have the unreasonable requests made of you by your relative been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, has the tension in your life been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, have your vacation activities and trips been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, has your nervousness & depression you have concerning your relationship with your relative been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, have your feelings that you have been taken advantage of by your relative been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, has the time you have to do your own work and daily chores been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, have the demands made by your relative that are over and above what s/he needs been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, has your anxiety about things been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Over the past week, has your time for friends and other relatives been...

a lot less than usual	a little less than usual	the same as usual	a little more than usual	a lot more than usual
--------------------------	-----------------------------	----------------------	-----------------------------	--------------------------

Social Activity

The following is a list of activities or situations in which you may have engaged over the last week. Please read the list, and for each activity indicate the number of times you engaged in it over the past week. If you can't remember *exactly* how many times each activity or situation took place don't worry - just have a guess.

Try to only count each instance of social activity once, even it falls into more than one category. For example, if you've already counted a visit from a neighbour in the first item, don't count it again in item 6.

	Activity	Number
1	Had friends / family round to visit	
2	A meal, drink, shopping trip, etc. with friends or family	
3	Visited friends or family at their home	
4	Chatted with friends or family on the phone	
5	Met with fellow members of a group or club	
6	Chatted to neighbours	
7	Spent time with someone you had not met before	
8	Joined a new club or society	
9	Made a new friend	
10	Made contact with someone you had not seen for a long time	
11	Made arrangements with friends or family a future visit / activity	
12	Any other social contact / activity with friends / or family	

How has the person you care for been over the last week? For each item below, please circle one response which best describes his / her condition in the last 7 days...

**OVER THE LAST WEEK...**

**1. When bathing or dressing, he/she required:**

- 0- no assistance
- 1- some assistance
- 2- maximum assistance

**OVER THE LAST WEEK...**

**2. With regard to walking, he / she:**

- 0- showed no sign of weakness
- 1- walked slowly without aid, or uses a stick
- 2- was unable to walk, or if able to walk, needed frame crutches, or someone by his / her side

**OVER THE LAST WEEK...**

**3. He / she was incontinent of urine and / or faeces (day or night):**

- 0- never
- 1- sometimes (once or twice last week)
- 2- frequently (3 times last week or more)

**OVER THE LAST WEEK...**

**4. He / she was in bed during the day (bed does not include couch, settee etc.)**

- 0- never
- 1- sometimes
- 2- almost always

**OVER THE LAST WEEK...**

**5. He / she was confused (unable to find way around, loses possessions, etc.):**

- 0- almost never confused
- 1- sometimes confused
- 2- almost always confused

**OVER THE LAST WEEK...**

**6. When left to his / her own devices, his / her appearance (clothes and / or hair) was:**

- 0- almost never disorderly
- 1- sometimes disorderly
- 2- almost always disorderly

**OVER THE LAST WEEK...**

**7. If allowed outside, he / she would have:**

- 0- never needed supervision
- 1- sometimes needed supervision
- 2- always needed supervision

**OVER THE LAST WEEK...**

**8. He / she helped out in the home:**

- 0- often
- 1- sometimes
- 2- never

**OVER THE LAST WEEK...**

**9. He / she kept himself/ herself occupied in a constructive or useful activity  
(worked, read, played games, hobbies, etc.)**

- 0- almost always occupied
- 1- sometimes occupied
- 2- almost never occupied

**OVER THE LAST WEEK...**

**10. He / she socialised with others:**

- 0- established a good relationship with others
- 1- had some difficulty in establishing good relationships
- 2- had a great deal of difficulty establishing good relationships

**OVER THE LAST WEEK...**

**11. He / she was willing to do things suggested or asked of him / her**

- 0 - often went along
- 1 - sometimes went along
- 2 - almost never went along

**OVER THE LAST WEEK...**

**12. He / she understood what you communicated to him / her (you may use speaking, writing, or gesturing):**

- 0- understood almost everything you communicate
- 1- understood some of what you communicate
- 2- understood almost nothing of what you communicate



OVER THE LAST WEEK...

13. He / she communicated in any manner (by speaking, writing or gesturing):

0- well enough to make him / herself easily understood at all times 0

1- could be understood sometimes or with some difficulty

2- could rarely or never be understood for whatever reason 2

OVER THE LAST WEEK...

14. He / she was objectionable to others during the day

(loud or constant talking, pilfering, soiling furniture, interfering with affairs of others):

0- rarely or never

1- sometimes

2- frequently

OVER THE LAST WEEK...

15. He / she was objectionable to others during the night (loud or constant talking, pilfering, soiling furniture, interfering with affairs of others, wandering about, etc.):

0- rarely or never

1- sometimes

2- frequently

OVER THE LAST WEEK...

16. He / she accused others of doing him / her bodily harm or stealing his / her personal possessions - *if you are sure the accusations were true, rate 0, otherwise rate 1 or 2:*

0- never

1- sometimes

2- frequently

OVER THE LAST WEEK...

17. He / she hoarded meaningless items (wads of paper, string, scraps of food, etc.):

0- never

1- sometimes

2- frequently

OVER THE LAST WEEK...

18. His / her sleep pattern at night was:

0- almost never awake

1- sometimes awake

2- often awake



# RESPITE CARE EVALUATION

We are interested in how you feel about the latest respite period. Please circle one response to indicate the extent to which you agree or disagree with each statement. Please don't leave any statements out – circle one response in each case.

This latest respite period enabled me to really relax and enjoy life

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
----------------------	----------	------------------------------	-------	-------------------

This latest respite period left me feeling fed up

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
----------------------	----------	------------------------------	-------	-------------------

This latest respite period helped me to 'recharge my batteries'

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
----------------------	----------	------------------------------	-------	-------------------

This latest respite period had a bad as well as good effect on me

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
----------------------	----------	------------------------------	-------	-------------------

I feel much beter after this respite period

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
----------------------	----------	------------------------------	-------	-------------------

I feel slightly worse after this respite period than before it

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
----------------------	----------	------------------------------	-------	-------------------

The respite enabled me to make contact with and enjoy the company of others

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
----------------------	----------	------------------------------	-------	-------------------

## Appendix 2: Documentation

**I feel I had the 'skills' to benefit fully from this latest respite period**

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
-------------------	----------	---------------------------	-------	----------------

**My spouse did not like this latest respite period**

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
-------------------	----------	---------------------------	-------	----------------

**The effect of this latest respite period on my spouse caused me concern**

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
-------------------	----------	---------------------------	-------	----------------

**I think my spouse enjoyed this latest respite period**

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
-------------------	----------	---------------------------	-------	----------------

**This latest respite period did my spouse a lot of good**

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
-------------------	----------	---------------------------	-------	----------------

**My spouse returned home worse after this latest respite period**

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
-------------------	----------	---------------------------	-------	----------------

**My spouse seems happier after this latest respite period**

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
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## **Appendix 2: Documentation**



University College London

# The Respite Care Study

## Information Sheet

We are a group of researchers at University College London. We are currently conducting research into the effects of residential respite care on carers of a spouse or partner with a long-term illness.

The aim of the research is to find out more about the extent to which carers experience respite, as well as their perceptions of how the respite period is experienced by their spouse or partner.

If you currently live with and care full-time for your spouse or partner then you can help us with this study. Taking part in the research involves receiving four visits, at home and at a time convenient to you, from a researcher. At each visit, the researcher will go through a questionnaire interview with you (lasting approximately 30 to 60 minutes). He or she will also ask you to provide saliva samples using cotton wool swabs (the samples are used to measure cortisol – a hormone thought to be related to stress).

All the information gathered, including via the saliva samples, is treated in the strictest confidence and will not be divulged to any third party.

You do not have to take part in the research if you do not want to. If you do decide to participate then you may withdraw at any time and without giving a reason.



University College London

## The Respite Care Study

### Consent Form

I have read the information sheet about this study - YES / NO

I have had a chance to ask questions and discuss this study - YES / NO

I have received satisfactory answers to my questions - YES / NO

I understand that I am free to withdraw from this study...

...at any time

...without giving a reason - YES / NO

Do you agree to take part in this study? - YES / NO

Signed..... Date .....

NAME \_\_\_\_\_

**Researcher:** I confirm that I have explained the nature and purpose of  
this study to the participant \_\_\_\_\_

